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The purpose of this study was to describe the quality of life in persons with end stage renal disease and examine factors that may affect quality of life. A revised version of Wilson and Cleary's model for health-related quality of life was used to guide the study. Biological factors (serum albumin and serum hemoglobin), symptoms (dialysis symptoms, anxiety, depression, and fatigue), functional status, general health perception, characteristics of the individual (age, gender, race/ ethnicity), and characteristics of the environment (time on dialysis, marital status, and socioeconomic status) were examined to determine their potential impact on overall quality of life.

A cross-sectional, correlational non-experimental study was conducted with a convenience sample of 73 persons undergoing hemodialysis at an outpatient dialysis center located within one city in central North Carolina. The majority of the participants was female (55%), African American (76%), not married (67%), and had incomes above the federal poverty level (56%). The mean age was 56 ($SD = 15.8$) and mean time on hemodialysis was 56 months ($SD = 58.3$). When all variables were included in the model, 61% of the variability in overall quality of life was explained. However, only the health-related variables of anxiety, depression, general health perception, and albumin significantly ($p < .05$) contributed to quality of life. Quality of life may be better predicted from psychological factors than physiological factors. Future studies should continue to identify factors that influence quality of life and determine interventions that enhance a person's sense of well-being.

USING THE REVISED WILSON AND CLEARY MODEL TO EXPLORE FACTORS
AFFECTING QUALITY OF LIFE IN PERSONS ON HEMODIALYSIS

by

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To Jay, Austin, and Zachary for their enduring love and patience.

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CHAPTER I

BACKGROUND

Introduction

Approximately 20 million Americans have some degree of kidney damage (American Nephrology Nurses Association, 2007), and more than 470,000 people live with end stage renal disease (ESRD), the final stage of chronic kidney disease (U.S. Renal Data System [USRDS], 2006). Each year more than 100,000 additional people are diagnosed with ESRD (USRDS, 2006). Incidence of ESRD has dramatically increased over the past decade, increasing from 261.3 per million population in 1994 to 348.6 per million in 2004 (Centers for Disease Control and Prevention, 2007). Because each person with ESRD uses approximately \$58,000 in Medicare dollars each year (USRDS, 2006), this increase in incidence of ESRD places a significant financial burden on the healthcare system. Given these figures, it is imperative that persons with ESRD receive not only cost-effective care, but also care that contributes to an acceptable quality of life. However, the quality of life for persons with ESRD has been shown to be lower than the general public (Cleary & Drennan, 2005; DeOreo, 1997; Ferrans & Powers, 1993; Frank, Auslander, & Weissgarten, 2003; Merkus et al., 1999), and in many dialysis centers, “life at any cost” is the unspoken rule (Russ, Shim, & Kaufman, 2007).

Quality of life for persons with ESRD is a growing concern among dialysis professionals for two reasons. First, ensuring the highest acceptable quality of life

constitutes ethical care. For years, determination of successful outcomes for persons with ESRD has been limited to clinically-focused measures of dialysis adequacy, such as acceptable laboratory values and inter-dialytic weight gain. However, even when these physiological measures are met, the person on dialysis may not experience a satisfactory quality of life. Therefore, other, more subjective, patient-focused measures are needed to augment the outcome evaluation for persons on dialysis. Quality of life determination is one such measure.

Second, quality of life measures may assist health care providers to track illness progression, including identification of the end of life. Chronic illness progression for persons with ESRD has been described as having three phases: crisis, chronic, and terminal (Jablonski, 2004). The crisis phase begins with a diagnosis of ESRD and the initiation of dialysis. The chronic phase is characterized by both stable and downward periods as the person undergoes multiple changes in condition which often necessitates short term hospitalization. This chronic phase continues in a downward saw tooth pattern until it becomes apparent the person will not rebound. This point is conceptualized as entering the terminal phase. The terminal phase is often characterized by frequent hospitalizations as the patient undergoes progressive deterioration that ultimately ends in death. Identifying the transition from the chronic phase to the terminal phase is difficult. Currently, no research is available to guide this determination, although recent studies have shown that as quality of life decreases, death grows nearer (Kalantar-Zadeh, Kopple, Block, & Humphreys, 2001; Lopes et al., 2007).

Knowing when the terminal phase is near may assist with implementing end-of-life interventions that can contribute to a good death (Kring, 2006). Hospice services specifically designed for persons with ESRD could provide much needed assistance with regard to advanced care planning, decisions to stop dialysis, symptom management after dialysis withdrawal, and psychological support. In addition to this ethical imperative, well planned, programmatic end-of-life care is also fiscally responsible. Healthcare in the last year of life accounts for 27.4% of Medicare spending (Hogan, Lunney, Gabel, & Lynn, 2001), and averages \$37, 581 per person (Hoover, Crystal, Kumar, Sambamoorthi, & Cantor, 2002). Much of this cost is due to technology needed to maintain life, such as ventilators. While using more healthcare resources at the end of life may be inevitable, *futile* healthcare is much more debatable; and *unwanted*, futile healthcare is simply immoral (Kring, 2007). Identifying the quality of life in persons with ESRD may help clinicians understand and support their patients' chronic illness progression, and noting significant declines may help identify the terminal phase, allowing for early end-of-life intervention.

The first step in identifying quality of life in persons with ESRD is to understand what factors influence quality of life. This information would provide a foundation to understand how quality of life can be used to identify phase transitions so that the chronic phase is managed with increased periods of stability, and to proactively assist persons with ESRD and their families to intentionally choose end-of-life experiences that are meaningful and spiritual, without unwanted, futile medical care.

Background and Significance

For persons with ESRD, renal replacement therapy is crucial or death will quickly ensue. Choices for renal replacement therapy include kidney transplantation, hemodialysis, or peritoneal dialysis. Because of a lack of kidneys for transplantation, only about 17% of persons on the kidney transplant list in 2004 actually received a kidney (USRDS, 2006). Thus, the majority of persons with ESRD require some type of dialysis to maintain life. Of those on dialysis, 93% receive hemodialysis, and 7% receive peritoneal dialysis (USRDS, 2006). Maintaining an acceptable quality of life for persons on hemodialysis can be challenging due to thrice weekly dialysis sessions, frequent surgical revisions of arterio-venous accesses, increased symptom burden, dietary restrictions, and complicated medication regimens. Therefore, quality of life is important to understand in this population for two reasons—to improve the quality of life, and to improve the quality of death.

Improving Quality of Life. According to the World Health Organization, quality of life is “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL Group, 1998, p. 1570). Knowing the quality of life, as well as factors that influence it, may assist clinicians in developing and implementing interventions targeted at improving it. One intervention to enhance quality of life is palliative care.

Palliative care provides the patient with life enhancing (rather than life sustaining) interventions in an effort to improve quality of life. Palliative care focuses on patients

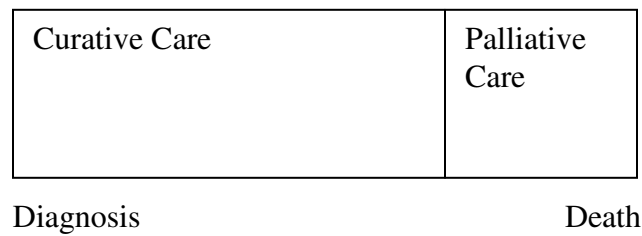
whose disease is not responsive to curative treatment and includes control of pain, other symptoms, as well as psychological, social, and spiritual problems (World Health Organization, 1990). The ultimate goal of palliative care is the best quality of life possible (Jablonski, 2007). A common misconception of palliative care is that it is implemented during the end of life. In fact, palliative care can be implemented at any point along the chronic illness trajectory and is compatible with active medical care. Indeed, the traditional model of palliative care did not allow for a palliative focus until curative care ceased (see Figure 1) (Jablonski, 2007).

The more modern integrated model of palliative care allows palliative care to be gradually incorporated as curative care becomes less effective. Jablonski (2007) further suggests that persons with ESRD require a more aggressive palliative model in which life sustaining care (like dialysis) is provided with equal measure as comfort care during the entire illness continuum from diagnosis to death. This holistic approach to care would allow persons with ESRD to benefit from the unique services of a dedicated palliative program that focuses on symptom management, advanced care planning, psychosocial and spiritual support, and assistance with decision-making near the end of life (Jablonski, 2007). Clearly, “active treatment and palliative care need not be mutually exclusive, especially in a disease that is at the same time chronic and life-limiting” (Jablonski, 2007, p.51). Unfortunately, the integrated model of palliative care has yet to be specifically funded in the United States (U.S.) healthcare system because, currently, most palliative programs are administered in conjunction with hospices, requiring a terminal diagnosis to

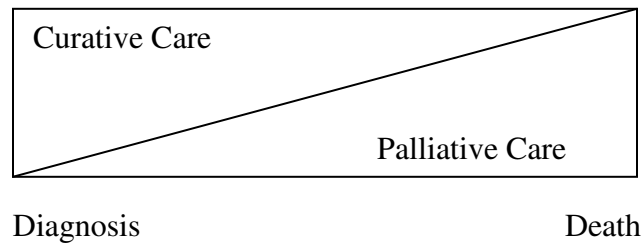
begin services. This arrangement leaves many persons with ESRD without access to palliative care until the end of life.

Figure 1. Models of palliative care.

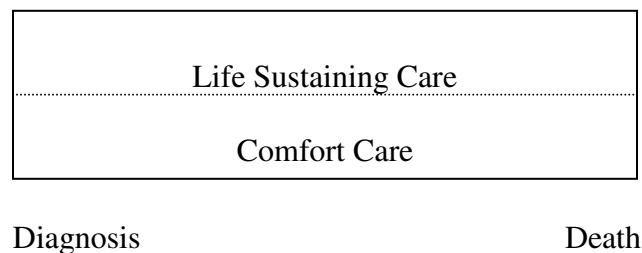
A. Traditional model of palliative care.



B. Integrated model of palliative care.



C. Jablonski's suggested model of palliative care for persons with ESRD.



A subgroup of the Robert Wood Johnson Foundation's program Promoting Excellence in End-of-Life Care examined ways to improve comfort and quality of life for persons with ESRD (End-Stage Renal Disease Workgroup, 2002). They strongly recommended that palliative services be increased for this group through their local dialysis centers, with funding provided by the Centers for Medicare and Medicaid Services (CMS). Some innovations in palliative care for persons with ESRD are already being developed. For example, in Canada, a proposal is being considered to improve the quality of life in the dialysis population through a comprehensive palliative care program that would manage disease burden as well as avoid futile use of medical resources through deliberate advanced care planning (Fainsinger, Davison, & Brenneis, 2003). In the U.S., the Renal Palliative Care Initiative was started as a collaboration between eight dialysis clinics and a medical center in western New England to integrate palliative medicine into nephrology medicine through education and collaboration with area hospices (Poppel, Cohen, & Germain, 2003). Unfortunately, they are not getting reimbursed for these efforts and few dialysis centers are willing to take on the extra expense. Both the Canadian and the U.S. initiatives demonstrate that a significant and targeted approach is needed to improve palliative services for this unique population.

Much work is still needed to determine the most effective palliative strategies for the ESRD population. In a pilot study of a small group of hemodialysis patients, researchers found that a palliative care intervention did not improve quality of life, symptom burden, or completion of advance directives (Weisbord et al., 2003). A significant barrier to success was the lack of follow through by nephrologists to

implement recommendations from the palliative care team. Provider engagement in the palliative process is crucial, as many patients will not request these services on their own. Indeed, 63% of persons on hemodialysis have never spoken about care at the end of life with their nephrologist (Weisbord et al., 2003). Nevertheless, targeted palliative services hold promise for improving the quality of life in this population.

Other interventions that may improve quality of life include support and encouragement strategies, patient education, exercise programs, employment support, and active self-management (Curtin, Mapes, Petillo, & Oberley, 2002; Molzahn, 2006). In addition, renal rehabilitation is a global term which encompasses any intervention designed to improve daily living for persons on dialysis. Originally conceived as a program to assist patients' return to the workforce (Oberley, Sadler, & Alt, 2000), renal rehabilitation has been reconceptualized due to the aging of the dialysis population as promoting optimal functioning and quality of life. The goal of renal rehabilitation is to increase physical activity in an effort to maintain or improve physical functioning to preserve independence with daily activities (Curtin, Lowrie, & DeOreo, 1999). With the onset of dialysis, role function often decreases due to the dependence on others for medical assistance and instrumental activities of daily living, such as shopping and housekeeping (Thomas-Hawkins, 2004). Intentionally targeting physical function may improve quality of life by allowing individuals to maintain personal activities of daily living, such as bathing and dressing. Unfortunately, rehabilitation of renal patients has received minimal attention (Thomas-Hawkins, 2004), most likely due to start up costs involved and limited research documenting potential cost savings. Even though ESRD is

not curable, “optimizing functioning is a real possibility and an achievable goal” (Curtin et al., 1999, p. 139). Nurses can play a vital role in developing, administering, and evaluating rehabilitation programs for persons with ESRD. Quality of life can be an important endpoint for validating the success of a renal rehabilitation program.

Thus, monitoring quality of life in persons with ESRD may assist with improving quality of life through progressive palliative care services, active self-management strategies, and renal rehabilitation. These interventions should assist persons with ESRD to achieve longer periods of stability during the chronic phase, minimize downward phases, and perceive a higher quality of life. Understanding factors contributing to quality of life may help identify which interventions could have the most influence on overall quality of life.

Improving Quality of Death. In addition to improving quality of life, evaluating quality of life may also improve quality of death. Research has shown that quality of life is related to end of life. Data from the International Dialysis Outcomes and Practice Patterns Study (DOPPS) provided evidence that lower quality of life scores were associated with greater risks for death and hospitalization (Lopes et al., 2003). In another study done in the U.S., a decreased quality of life in patients on hemodialysis also significantly correlated with death and hospitalization (Kalantar-Zadeh et al., 2001). Therefore, monitoring a person’s quality of life, or the factors influencing it, may assist in determining the end of life.

Knowing that the end of life is near provides persons with ESRD and their families the option of exploring the decision to stop dialysis and enter into hospice care.

Although hospice care is different from palliative care, they are often associated together. This confusion is due to the fact that most palliative care teams work through hospice agencies and are therefore considered an end-of-life support. Hospice care has been shown to improve pain assessment and management, improve bereavement outcomes, and improve overall satisfaction with end of life care (Casarett & Quill, 2007). However, these services are severely underutilized by persons with ESRD. According to the National Hospice and Palliative Care Organization, 46% of hospice patients have a cancer diagnosis, while ESRD only comprises 3.1% (National Hospice and Palliative Care Organization, 2006). Another study found that hospice was involved in less than 10% of dialysis deaths (Holley, 2005).

The reasons for underutilization of hospice services in persons with ESRD are many. For one, unless an intentional decision to stop dialysis is made, it is very difficult to identify the dying trajectory in persons with ESRD. The typical saw tooth illness trajectory of life-threatening acute episodes followed by considerable recoveries blurs the underlying chronic downward progression. To qualify for hospice services, the patient's physician must determine that the patient has approximately six months to live. For dialysis patients that often spiral towards death only to rebound, this determination is very difficult (Davison & Torgunrud, 2007). In addition, when hospice services are requested, the patient's Medicare benefit defaults to the hospice agency which must provide all final health-related needs, including dialysis. Due to the expense, most hospices cannot afford to pay for dialysis services for an extended period of time (Owens, 2006). Therefore, hospices do not typically accept patients with ESRD unless dialysis

treatments have been formally stopped. The Robert Wood Johnson Foundation's end of life workgroup recommended that the Medicare hospice benefit be applied to ESRD patients who are certified by their physicians as terminally ill, but choose to continue dialysis until they die (End-Stage Renal Disease Workgroup, 2002). To date, this recommendation has not been heeded. Lastly, time is an issue for mobilizing hospice services. Patients and families often need to be "eased" into hospice as they readjust their perceptions of the gravity of the patient's current situation (Casarett & Quill, 2007). Stopping dialysis usually results in death within two weeks (Moss, 2001), thus depriving the patient and family of time to adjust to a terminal prognosis and accepting hospice services.

These barriers to accessing hospice services need to be overcome. Determining factors related to quality of life may provide essential information in monitoring the quality of life of persons with ESRD, and thus may assist health care providers with earlier recognition of the terminal phase of the chronic illness trajectory. This earlier determination may allow for essential time to more effectively transition a person with ESRD into hospice services.

Both palliative care services and hospice services are underutilized in the ESRD population, in large part due to CMS reimbursement policies. Without doubt, "patients should not be asked to choose between life-saving dialysis and palliative care" (Jablonski, 2007, p. 57). As envisioned by Jablonski's schema (see Figure 1), palliative services need to coincide with dialysis therapy throughout the entire chronic illness trajectory. Research into the quality of life of persons with ESRD, including an

understanding of which factors contribute to variances in quality of life, may help inform clinicians and policy makers regarding this unique chronic illness trajectory and the interventions that are most supportive and cost-effective.

Much work is needed to improve the quality of life as well as the quality of dying for persons with ESRD. While the quality of life of persons with ESRD has been examined in numerous studies (Frank et al., 2003; Loos, Briancon, Frimat, Hanesse, & Kessler, 2003; Weisbord et al., 2003), none have helped to inform the progression along the chronic illness trajectory. Without a clearer understanding of where persons are on the continuum, interventions to improve quality of life may be misguided and wasted. Quality of life is an important measure for clinicians and researchers as they target palliative interventions that can maximize quality of life. Quality of life may also be an important measure to assist with the identification of the terminal phase and how early hospice services can improve the end of life, including better management of limited fiscal resources. The first step in implementing this research trajectory is understanding the quality of life of persons with ESRD, and what factors influence overall quality of life.

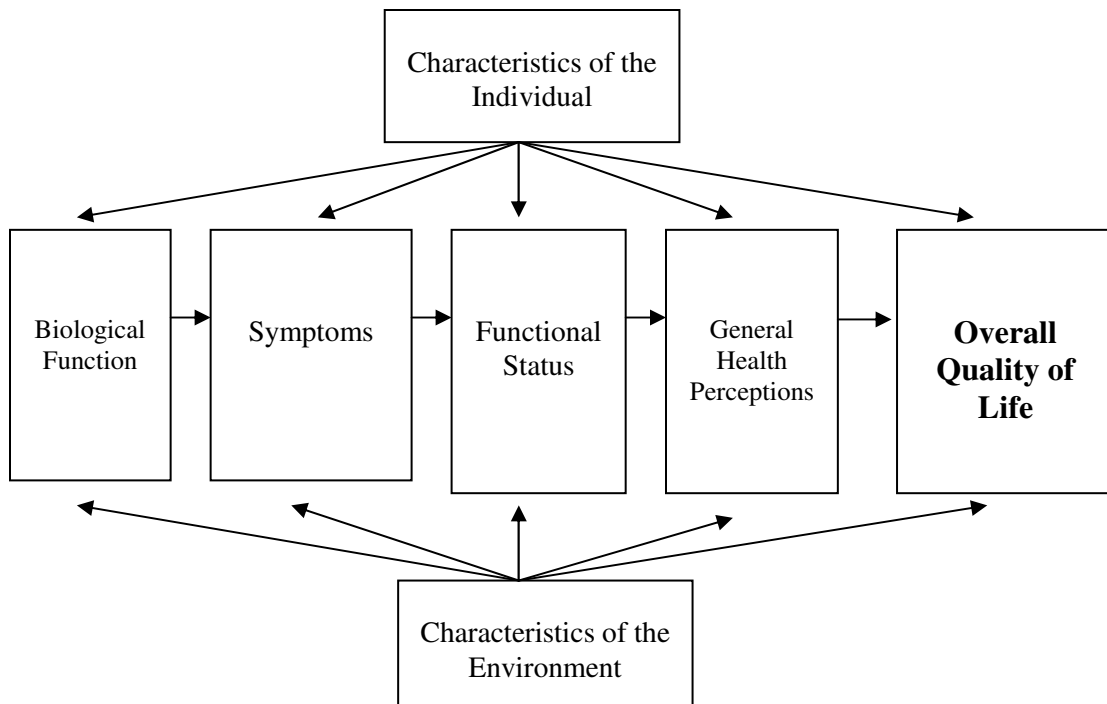
Purpose

The purpose of this study was to describe the quality of life in persons with ESRD and examine factors which influence the quality of life.

Conceptual Framework

A revised version of Wilson and Cleary's (1995) model for health-related quality of life (Ferrans et al., 2005) was used to guide this study (see Figure 2).

Figure 2. Revised Wilson and Cleary Model of Health-Related Quality of Life



According to this model, there are four main determinants of overall quality of life:

biological function, symptoms, functional status, and general health perceptions.

Characteristics of the individual and characteristics of the environment influence all of these determinants, as well as quality of life.

Biological function includes the physiological processes that support life (Ferrans et al., 2005) and is the most fundamental determinant of health status (Wilson & Cleary, 1995). Biological function focuses on the performance of cells and organ systems and can often be measured through lab tests, physical assessment, and medical diagnosis.

Alterations in biological function can impact all the subsequent determinants of quality of

life, including symptoms, functional status, and general health perceptions. The focus of medical intervention is often to improve outcomes in this domain.

Moving along the model from biological function to symptoms requires a shift from a cellular level to the organism as a whole (Ferrans et al., 2005). Symptoms include “a patient’s perception of an abnormal physical, emotional, or cognitive state” (Wilson & Cleary, 1995, p. 61). While symptoms are often related to biological function, they are different. Sometimes biological changes do not produce symptoms, and sometimes symptoms are perceived in the absence of a biological cause. This feature makes symptoms totally unique to the individual and may differ from someone who is experiencing the same disease process. It is important to measure the influence of symptoms on overall quality of life.

The next level of the revised Wilson and Cleary model is functional status, which assesses the ability to perform certain tasks (Wilson & Cleary, 1995) and is often influenced by biological function and symptoms. However, it is once again important to measure functional status as a separate variable because it may not be completely correlated with biological function or symptoms. Four domains of functioning that are often measured are physical, social, role, and psychological (Wilson & Cleary, 1995). Ferrans et al. (2005) use a more traditional approach in their revised model by focusing on the effects of disability on functional status and its impact on daily life.

The next level of the model is general health perceptions, a representation of all health concepts together, plus others that may not be depicted by the model (Wilson & Cleary, 1995). It is subjective in nature and allows for the individual to summarize all the

preceding concepts, placing value on the importance of each variable, to generate a summation of individual health. It is a different concept than simply adding the preceding concepts (Ferrans et al., 2005) because it can include more than those concepts and is heavily subjective. General health perception is most commonly measured with a single global question, indicating an overall health rating on a Likert-type scale from poor to excellent.

All of these concepts ultimately impact overall quality of life which is a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/ her (Ferrans et al., 2005). Due to the subjective nature of many of the antecedents, overall quality of life is subjective and individualized. It may also be conceptualized as complex and multidimensional. Using exploratory factor analysis, Ferrans and Powers (1992) identified four factors which explained 91% of the total variance in Quality of Life Index scores: (a) health and functioning, (b) socioeconomic, (c) psychological/ spiritual, and (d) family. Thus, use of the Quality of Life Index allows exploration of overall quality of life, as well as four salient domains. The health and functioning domain has a significant influence on the perception of the quality of one's life. In fact, the concept "quality of life" is often referred to as "health-related quality of life" by health care providers and researchers. This conceptual ambiguity will be explored in more depth in chapter two.

Characteristics of the individual are categorized as demographic, developmental, psychological, and biological factors that influence health outcomes (Ferrans et al., 2005). Common demographic characteristics that have been linked with health include

sex, age, and ethnicity. They are usually not modifiable, but provide information regarding who to target for health interventions. Developmental factors are not static, but are also not modifiable. However, they should be considered when deciding which types of health interventions will be successful. Psychological factors are dynamic and also modifiable. They include cognitive processes which alter perceptions, such as motivation and beliefs. Biological factors are the genetically linked characteristics that may manifest as disease, thus impacting biological function.

Characteristics of the environment are either social or physical (Ferrans et al., 2005). Social characteristics include the influence of significant others, such as marriage partners, as well as the social milieu, such as the specific culture of a hemodialysis clinic, on health behavior. Physical characteristics include the distinctive attributes of settings which may influence health outcomes, such as neighborhood pollution or workplace exercise facilities.

The model depicts a unidirectional flow of factors toward overall quality of life. However, these arrows only represent the typical causal pathway (Ferrans et al., 2005). It is conceivable and probable that any arrow could point in the opposite direction, representing the complexity of the interactions among the various factors impacting quality of life.

Specific Aims

The specific aims were:

1. Describe the quality of life in persons with ESRD.

Q1: What is the quality of life in persons with ESRD?

2. Examine factors that may affect quality of life in persons with ESRD.

Q2: Do biological function (serum albumin and serum hemoglobin), symptoms (dialysis symptoms, anxiety, depression, and fatigue), functional status, and general health perception explain overall quality of life in persons with ESRD?

Q3: Do biological function (serum albumin and serum hemoglobin), symptoms (dialysis symptoms, anxiety, depression, and fatigue), functional status, general health perception, characteristics of the individual (age, gender, and race) and characteristics of the environment (marital status, socioeconomic status, and time on hemodialysis) explain overall quality of life in persons with ESRD?

Q4: Do biological function (serum albumin and serum hemoglobin), symptoms (dialysis symptoms, anxiety, depression, and fatigue), functional status, general health perception, characteristics of the individual (age, gender, and race) and characteristics of the environment (marital status, socioeconomic status, and time on hemodialysis) explain *dimensions* of quality of life (health and functioning, socioeconomic, psychological/ spiritual, and family) in persons with ESRD?

Q5: When controlling for characteristics of the individual (age, gender, and race) and characteristics of the environment (marital status, socioeconomic status, and time on hemodialysis), do biological function (serum albumin and serum hemoglobin), symptoms (dialysis symptoms, anxiety, depression, and fatigue), functional status, and general health perception explain overall quality of life in persons with ESRD?

Definitions

The following terms are defined for the purpose of this study:

1. **Persons with end stage renal disease (ESRD):** Persons who have been diagnosed by a nephrologist as having stage 5 chronic kidney disease requiring renal replacement therapy, such as dialysis. For this study, only persons on hemodialysis were included.
2. **Hemodialysis:** A process by which blood is artificially cleansed in the absence of normal kidney function. During this process, blood is diverted from the body through an arterio-venous access, pumped through an extra-corporeal circuit where waste products and excess fluid diffuse through a semipermeable membrane for disposal, and the cleansed blood is returned to the body. All persons attending the dialysis clinic and connected to the hemodialysis machine via an arterio-venous access were considered to be undergoing hemodialysis.
3. **Quality of life:** A person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/ her (Ferrans et al., 2005). For this study, quality of life was operationalized as the score on the Quality of Life Index- Dialysis Version- III (Ferrans & Powers, 1985).
4. **Biological function:** Molecular, cellular, and organ processes that support life (Wilson & Cleary, 1995). For this study, biological function was measured by the most recently documented serum albumin (grams/ Liter) and serum hemoglobin level (grams/ deciliter) in the participant's medical record.
5. **Symptoms:** A person's perception of an abnormal physical, emotional, or cognitive state (Ferrans et al., 2005; Wilson & Cleary, 1995). For this study, symptoms were

- measured in three separate ways: (a) the score on the Dialysis Symptom Index (Weisbord et al., 2004), (b) the score on the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), and (c) the score in millimeters on a fatigue visual analog scale (Wolfe, 2004).
6. Functional status: The ability to perform tasks of daily living, including personal, instrumental, and social tasks, and the actual performance of these tasks, as measured by the score on the Inventory of Functional Status- Dialysis (Thomas-Hawkins, 2004).
 7. General Health Perceptions: An overall perception of wellness that is individualized and subjective. For this study, general health perceptions was operationalized as the score on one global question, “How would you rate your health on a scale from 1 to 10, with 1 = poor and 10 = excellent?” (Ferrans et al., 2005).
 8. Characteristics of the individual: Demographic, developmental, psychological, and biological factors that influence health outcomes (Ferrans et al., 2005). For this study, characteristics of the individual was the determination of three representative variables: (a) age of the participant in years according to the medical record, (b) gender (male or female) according to the medical record, and (c) self-reported race (white, African American, Hispanic, or other).
 9. Characteristics of the environment: Social or physical factors present in the person’s setting or situation which influence health. For this study, characteristics of the environment was the determination of three representative variables: (a) self-reported marital status (single, married, separated, divorced, or widowed), (b) self-reported

poverty status (poverty/ no poverty) according to a poverty income grid, and (c) time on hemodialysis in months according to the medical record, including episodes separated by periods of peritoneal dialysis or transplantation.

Assumptions

Assumptions underlie the methods used in this study. The first assumption addresses the belief that quality of life exists as a multi-dimensional construct. In addition, abstract and unobservable concepts, such as symptom burden and health perception, can be quantified and tested through instrumentation and statistical analysis. Furthermore, persons with ESRD will accurately and honestly answer questions that measure symptom burden, physical function, general health perception, quality of life, individual characteristics, and environmental characteristics. The final assumption is that data from the medical record reflect reality.

Summary

The purpose of this research was to describe the quality of life of persons with ESRD, including influencing factors. A revised version of Wilson and Cleary's model for health-related quality of life (Ferrans et al., 2005) was used to guide the study. The results of this study will assist investigators to begin a larger research trajectory of monitoring quality of life and determining interventions to maximize it by targeting influencing factors. In addition, quantification of quality of life may assist researchers in determining the terminal phase of the chronic illness trajectory allowing for early mobilization of hospice services at the end of life for persons with ESRD.

CHAPTER II

LITERATURE REVIEW

Introduction

The term “quality of life” entered the American vocabulary after World War II to emphasize that “the good life” was more than just wealth (Campbell, Converse, & Rodgers, 1976). Since then, it has been an important concept for health care providers as well as social policy makers. However, the term is multidimensional and no clear definition has been agreed upon by those who use the phrase (Ferrans & Powers, 1992; Kimmel, 2000), including scientists who quantify it. The ambiguity surrounding the term is “complex and contentious” (Tyrrell, Paturel, Cadec, Capezzali, & Poussin, 2005, p. 375). This conceptual confusion has created a significant shortcoming in the literature when quality of life studies are compared and synthesized.

Current Theoretical Views on Quality of Life

Quality of life is most often described in one of two ways: satisfaction or happiness (Ferrans & Powers, 1992). While happiness tends to denote a more fleeting, unstable emotion, satisfaction implies a more permanent state that stems from core values. While social scientists were grappling with the philosophical distinctions between happiness and satisfaction, health providers became interested in the concept as it related to their patients. Because health has such a large impact on perceived quality of

life, the phrase began to take on even more meanings, including well-being, psychosocial adjustment, physical functioning, symptoms and health status (Ferrans et al., 2005).

Most scientists agree that quality of life is composed of various dimensions which impact it, but no consensus has been reached on the essential dimensions. In a synthesis of various studies, quality of life dimensions have included life satisfaction, socioeconomic status, physical health, affect, perceived stress, friendship, family, marriage, life goals, housing and neighborhood, city and nation, self-esteem, depression, psychological defense mechanisms, and coping (Ferrans & Powers, 1985). In an attempt to clarify the conceptual confusion, the term “health-related quality of life” was coined to denote the effects of health, illness, and treatment on overall quality of life (Ferrans et al., 2005; Kimmel, 2000), or the impact of disease on important areas of one’s life (Phillips, Davies, & White, 2001). Most health-related quality of life studies include a physical functioning measure (Laws, Tapsell, & Kelly, 2000; Painter, Carlson, Carey, Paul, & Myll, 2000; Patel, Shah, Peterson, & Kimmel, 2002; Phillips et al., 2001), and sometimes this is the only measure of health-related quality of life (Kimmel, 2000).

From this conceptual stance, health-related quality of life does not include factors such as cultural, political, or societal attributes (Ferrans et al., 2005). For nurses who most often subscribe to a holistic worldview, however, virtually all areas of life are affected by health and conversely, health affects all areas of one’s life. It is virtually impossible to separate out the influence of cultural, political, or societal attributes on health, and thus quality of life. For example, political oppression can lead to decreased access to care, and cultural dietary practices can undermine therapeutic diets. Viewed

through a holistic lens, human beings are bio-psycho-social beings. Thus, their quality of life is more than their health.

Since the term “health-related quality of life” started being used, it has been almost impossible to separate it from the more global “quality of life.” The two terms are often used interchangeably within the same research report (Bakewell, Higgins, & Edmunds, 2001; Drayer et al., 2006; Morsch, Goncalves, & Barros, 2006) without any conceptual clarification. In general, however, health researchers tend to subscribe to one of two views: (a) a holistic, global framework; or (b) a disease-based, deficit framework. Proponents of both views may interchange the terms “quality of life” and “health-related quality of life,” so it may not always be clear which perspective guides the study. An example of a global framework is the Register theory of Generative Quality of Life for the Elderly (Register & Herman, 2006). This middle-range theory incorporates six ways that people are connected to salient life dimensions that together impact quality of life: metaphysically connected, spiritually connected, biologically connected, connected to others, environmentally connected, and connected to society. The person is viewed in totality and health may impact connections in any of the forces. An example of a disease-based, deficit framework is Wilson and Cleary’s health-related quality of life conceptual model (Wilson & Cleary, 1995). In developing their model, Wilson and Cleary wanted to focus on the physical components of quality of life. They determined a need for a physiologically-based framework because previous models had “foundations in sociology, psychology, and economics and use concepts and methodologies often

foreign to physicians and clinical researchers” (p. 59). Therefore, their model emphasizes the impact of health and disease on quality of life.

In addition to Register and Herman (2006) and Wilson and Cleary (1995), other conceptual models of quality of life exist, including models from other disciplines, such as the economically-based model depicting a causal chain of well-being involving perceived income adequacy (Cummins, 2005). Health researchers have not endorsed any one model or even narrowed the field. Indeed, many researchers do not refer to any specific theoretical framework of any kind when reporting their research results (Loos et al., 2003; Lopes et al., 2003; Merkus et al., 1999; Sesso, Rodrigues-Neto, & Ferraz, 2003).

Without conceptual clarity, one must examine the domains often associated with quality of life and health-related quality of life research to better understand the conceptual foundation. Once again, no consensus has been reached regarding the salient domains that must be included in any measure of quality of life. Life satisfaction is often included in measures of quality of life (Ferrans & Powers, 1985), and one of the earliest theorists in the quality of life field conceptualized quality of life as a fit between aspirations and actual life experiences (Campbell, 1981). The most common domains found in the health literature, including studies involving persons with ESRD (Cleary & Drennan, 2005; Tyrrell et al., 2005), usually include at least physical, psychological, and social components. Other domains often include work life (Phillips et al., 2001), spirituality (Patel et al., 2002; Weisbord et al., 2003), general health perceptions (Phillips

et al., 2001), self-esteem (George & Bearon, 1980), socioeconomic status (George & Bearon, 1980), and activity level (Phillips et al., 2001).

Although identifying domains associated with a concept is helpful in understanding causal and influential relationships, it does not clearly identify the meaning of the concept. Unfortunately, defining the term “quality of life” has also been elusive. Wilson and Cleary (1995) did not define the term. They stated, “Health status and health-related quality of life can refer to different concepts, but in this article we use the terms interchangeably” (p. 60). Ferrans and Powers (1992) specifically define quality of life as “a person’s sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/ her” (p. 29). This definition includes the satisfaction factor, which denotes a more permanent kind of well-being, as well as the belief that different people have different values which impact their perception of quality of life.

Quality of Life in Persons with ESRD

Quality of life is a concept that has been studied in persons with ESRD. Findings indicate that persons with ESRD have a lower quality of life than the general public (Cleary & Drennan, 2005; DeOreo, 1997; Ferrans & Powers, 1993; Frank et al., 2003; Merkus et al., 1999). This lower quality of life may be related to the complications associated with ESRD that significantly impact quality of life (Phillips et al., 2001). More concerning is that persons with ESRD have a lower quality of life than persons with other chronic illnesses (Loos et al., 2003), and that quality of life is correlated with hospitalization and death in persons with ESRD (DeOreo, 1997). However, these studies

and others using quality of life as a variable are difficult to interpret and synthesize due to a lack of conceptual clarity. The authors often did not provide a definition of quality of life (Patel et al., 2002; Weisbord et al., 2003), explicate specific domains associated with quality of life (Laws et al., 2000; Sesso et al., 2003), nor specify a conceptual model which guided the study design and analysis (Kalantar-Zadeh et al., 2001; Merkus et al., 1999). The term “health-related quality of life” was more prevalent than the more global “quality of life,” although many studies interchanged the two terms (Bakewell et al., 2001; Drayer et al., 2006; Morsch et al., 2006). Unfortunately, without conceptual detail, it is unclear what was being studied.

Only a few studies on quality of life in persons with ESRD were found that made an attempt at a definition of quality of life or health-related quality of life. Many reports stated in various ways that quality of life (or health-related quality of life) is a patient’s subjective sense of well-being (Baiardi et al., 2002; Ferrans & Powers, 1993; Greene, 2005; Kalantar-Zadeh et al., 2001). Other authors used the medical model approach and defined the term according to self-reported health status and functioning (Curtin, Bultman, Thomas-Hawkins, Walters, & Schatell, 2002; DeOreo, 1997; Morsch et al., 2006; Painter et al., 2000). One study used both (Frank et al., 2003). The majority of studies, however, did not attempt to define the concept or clarify the salient domains associated with it.

Without clearly delineated domains and definitions, conceptual clarity can still be achieved through the application of a conceptual framework, model, or theory. However, this, too, is missing from the ESRD literature. From 25 studies examined for domains

and definitions, only three provided a theoretical foundation in which to ground their research. One used Wilson and Cleary's health-related quality of life framework (Frank et al., 2003), and another used a palliative care model which was more appropriate for the nature of the research (Jablonski, 2007). The third study was done by Ferrans and Powers (1993) and used a conceptual approach to quality of life derived from their Quality of Life Index. Interestingly, these studies were conducted by social workers (Frank et al., 2003) and nurses (Ferrans & Powers, 1993; Jablonski, 2007). One caveat to the lack of quality of life definitions, domains and frameworks must be mentioned. Many journals do not have space for elucidating conceptual frameworks which provide the foundation for scientific inquiry. However, one must wonder whether conceptual haze and not journal space is more the issue. By not including at least the name and reference of the guiding framework, results can not be readily synthesized with similar studies to support and revise existing patterns of thought around a phenomenon. In addition, the results may be vulnerable to misinterpretation if consumers of research reports must align the findings within their own conceptual understanding. These consequences risk impeding scientific knowledge development.

Without a definition or conceptual framework, another way to understand a concept is to examine the instruments used to measure it. Often the subscales of an instrument are the conceptual domains, thereby providing theoretical insight. Most subscales are derived from a statistical factor analysis. By far, the most popular tool in the ESRD literature on quality of life is the Medical Outcomes Study 36-item Short Form Health Survey (SF-36) (Ware & Sherbourne, 1992) and the Kidney Disease Quality of

Life Short Form (KDQOL-SF) which uses the SF-36 as its core (Korevaar et al., 2002). The SF-36 is a general health questionnaire and is referred to in studies as a measure of quality of life, health-related quality of life, physical and mental functioning, patient-assessed functional health status, general health, and health outcomes. The SF-36 has 36 items and eight scales: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health. In addition to scale scores, two summary scores are provided: physical component summary and mental component summary. The instrument items are all geared toward health-related concerns. For example, an item on the social functioning scale asks to what extent physical health or emotional problems (emphasis included in the scale) have interfered with social activities. The KDQOL-SF includes all the SF-36 items, plus 43 additional questions to assess concerns specific to persons on hemodialysis. It retains the physical component summary scale and the mental component summary scale of the SF-36, plus a kidney disease component summary.

In a review of ESRD quality of life studies, Kimmel (2000) reported that a wide range of instruments have been used to measure quality of life and health-related quality of life in this population, including the Karnofsky Performance Scale (a physical functioning scale), the Beck Depression Inventory, the Multidimensional Scale of Perceived Social Support, and the Illness Effects Questionnaire. Clearly, from this listing, conceptual incongruence exists. It appears that one aspect or domain of quality of life may be being used synonymously with the larger construct of quality of life. Kimmel reviewed studies primarily from medical journals, which often do not have the holistic

focus that nursing journals do. Thus, the concept of quality of life was viewed more narrowly as health status, and various measures of health status were used as measures of quality of life.

The other quality of life instrument that has been used with some frequency in the ESRD population is Ferrans and Powers' (1985) Quality of Life Index- Dialysis Version. This instrument has four subscales: health and functioning, social and economic, psychological and spiritual, and family. This structure was derived from factor analysis, and the authors used this grouping to describe a conceptual framework (Ferrans, 1996). The underlying domains are more holistic than the SF-36. Recent use of this tool was by non-physicians—dietitians (Laws et al., 2000), physical therapists (Greene, 2005), and nurses (Bihl, Ferrans, & Powers, 1988; Ferrans & Powers, 1993; Jablonski, 2007).

The quality of life studies involving persons with ESRD (and most probably other patient populations) are conceptually weak. Without a theoretical basis, consistently delineated domains, common definition, nor an agreed upon term for the concept, it is difficult to interpret and synthesize the findings. One could argue that instead of measuring quality of *life*, the actual variable being measured is quality of *health*. While this may be the intent with the use of the phrase “health-related quality of life,” the resulting confusion has hampered efforts at measuring the more holistic *quality of life*.

Research with persons with ESRD is needed which explores quality of life conceptualized as a holistic expression summarizing the totality of satisfaction with one's life. While health is a dominant component of this concept, it cannot be separated from other influences which impact one's subjective perception regarding well-being. The

reductionistic efforts of previous studies to explain quality of life by compartmentalizing the health-related factors has resulted in uninterpretable findings. For example, the studies which have found that the quality of life for persons with ESRD is lower than the general public (Cleary & Drennan, 2005; DeOreo, 1997; Frank et al., 2003; Merkus et al., 1999) leaves one to question whether the *quality of life* is lower or whether *health status* is lower. The SF-36 queries, “To what extent do physical health or emotional problems interfere with social activities?” Certainly persons undergoing thrice weekly hemodialysis will experience interference with social activities due to their illness. However, this does not measure the quality of those relationships nor the satisfaction derived from them.

One holistic model that may provide theoretical strength to quality of life research is the revised Wilson and Cleary model of health-related quality of life (Ferrans et al., 2005). Although the conceptual model is labeled a *health-related* quality of life model, it is more of a quality of life model than a health-related quality of life model. The basis for this contention lies in examination of the characteristics of the individual and the characteristics of the environment (see Figure 2). Ferrans et al. elucidated an ecological model of influence for these two variables which expanded their scope well beyond health-related control. By including the influence of intrapersonal, interpersonal, institutional, community, and public policy factors, overall quality of life is affected by more than health. The fact that the arrows emanating from characteristics of the individual and the characteristics of the environment point not only to the antecedents of quality of life, but directly to overall quality of life as well, indicate that their influence

on quality of life need not be exclusively mediated by health-related factors, such as biological function, symptoms, and functional status. Both Ferrans et al. and Wilson and Cleary indicate that the direction of the arrows can be reversed to show reciprocal relationships, and that the absence of arrows between levels does not imply that relationships do not exist. This complexity allows for characteristics of the environment to influence characteristics of the individual, which can impact overall quality of life. This pathway is important because it signifies that a completely non-health-related factor, such as lack of local entertainment, can influence the psychological component of characteristics of the individual, which can in turn effect the perception of overall quality of life.

Biological Function

According to the revised Wilson and Cleary model of health-related quality of life (Ferrans et al., 2005), four factors—biological function, symptoms, functional status, and general health perceptions—influence overall quality of life. Biological function is the most basic determinant of quality of life because it involves cellular and organ level impairment. Two biological factors that may impact quality of life in persons with ESRD are malnutrition and anemia.

Many factors contribute to malnutrition in renal failure, including anorexia, metabolic acidosis, endocrine disorders, co-morbidities, systemic inflammation, reduced nutrient intake, inadequate dialysis, intra-dialytic protein losses, depression, and the cost of high quality food (Goldstein-Fuchs, 2006). These factors deplete the amount of protein available to meet essential amino acid requirements by the body for cellular

generation. Of the proteins lost daily, 50-80% is as albumin (Goldstein-Fuchs, 2006). Severe malnutrition has been associated with decreased quality of life (Laws et al., 2000), and albumin levels have been positively correlated with the physical component scale of the SF-36 (Lopes et al., 2007; Morsch et al., 2006), as well as the mental component scale (Frank et al., 2003; Kalantar-Zadeh et al., 2001). One study did not find a significant correlation between albumin and quality of life (Patel et al., 2002). However, this study used a single global question to assess quality of life, which may be a narrow conceptualization of quality of life according to the revised Wilson and Cleary conceptual model (Ferrans et al., 2005). In addition, low albumin has been identified as a significant predictor of mortality (DeOreo, 1997; Lowrie & Lew, 1990). Therefore, studies examining albumin as an important component of biological function are needed.

Anemia has also been shown to impact quality of life in persons with ESRD. Low hemoglobin levels result in poor oxygen-carrying capacity of red blood cells. The associated symptoms include fatigue, poor concentration, decreased appetite, palpitations, angina, and reduced libido (Candela & Parker, 2006). Although studies have shown that hemoglobin is positively correlated with quality of life (Baiardi et al., 2002; Lopes et al., 2007; Morsch et al., 2006), some studies have not shown such a correlation (Frank et al., 2003; Kalantar-Zadeh et al., 2001; Patel et al., 2002). The reason for this inconsistency may be the measurement of quality of life. One study used a single global measure (Patel et al., 2002), and the other two used the SF-36, a narrow, health-related instrument to quantify quality of life. Another reason for inconsistent correlations may be that most persons with ESRD receive erythropoietin therapy to increase red blood cell production.

This therapy has significantly decreased anemia in the ESRD population (Candela & Parker, 2006). However, other factors can also contribute to anemia, including hyperparathyroidism, iron and folate deficiency, decreased red blood cell lifespan due to uremia, and increased potential for bleeding due to platelet dysfunction (Candela & Parker, 2006). In addition, anemia management can be very challenging for the health care provider due to individual patient differences creating inconsistent responses to therapy. Thus, maintaining hemoglobin levels according to published clinical practice guidelines is difficult and both high and low hemoglobin levels are common (Candela & Parker, 2006). Therefore, the role of anemia as a biological factor impacting quality of life in persons with ESRD is still unclear and warrants further research.

Symptoms

According to the revised Wilson and Cleary model of quality of life (Ferrans et al., 2005), the physical and emotional burden from symptoms is crucial in understanding quality of life. Often, health care providers do not understand the value that hemodialysis patients place on their symptoms (Weisbord et al., 2004). In a systematic review of 59 studies which addressed symptoms experienced by persons on hemodialysis (Murtagh, Addington-Hall, & Higginson, 2007), the top reported symptoms and their weighted mean prevalence were: fatigue (71%), pruritis (55%), constipation (53%), anorexia (49%), pain (47%), sleep disturbance (44%), anxiety (38%), dyspnea (35%), nausea (33%), restless legs (30%), and depression (27%). The wide range of symptoms has also been reported in another study in which 22 out of 47 symptoms were experienced “at least some of the time” (Curtin, Bultman, et al., 2002). The mean

number of symptoms experienced per person has been reported as 5.67 (Jablonski, 2007), 7.7 (Frank et al., 2003), and 9.8 (Weisbord et al., 2004). Although these studies are not comparable due to the wide range of assessment tools used, clearly persons with ESRD experience many symptoms related to their disease. Symptom distress in the ESRD population has been positively correlated with co-morbidities (Weisbord et al., 2003), and negatively correlated with functional status (Thomas-Hawkins, 2000). In addition, symptom burden has been correlated with a decreased quality of life (Curtin, Bultman, et al., 2002; Weisbord et al., 2003). One study found that symptom scores, level of relief, and satisfaction with relief accounted for 28% of the variance in quality of life (Jablonski, 2007); while another found that severity of symptoms accounted for 44% variance in the physical component scale of quality of life (Frank et al., 2003). Besides the fact that symptoms are a main variable in the revised Wilson and Cleary quality of life model, the significant influence of dialysis symptoms on quality of life necessitates further validation to build evidence for palliative services in this vulnerable population.

A few symptoms experienced by persons on hemodialysis have been explored in the literature in more depth. Fatigue is the most commonly reported symptom by persons undergoing hemodialysis (Murtagh et al., 2007). Prevalence has been reported at 74% (Weisbord et al., 2003), 77% (Jablonski, 2007), 82% (Merkus et al., 1999), 84% (Frank et al., 2003), and 90% (Curtin, Bultman, et al., 2002). Fatigue is often underreported in the hemodialysis population because patients expect fatigue to go along with chronic disease (Srivastava, 1986). However, many times fatigue can be lessened if the underlying cause(s), such as anemia, depression, dialysis inadequacy, or the effects of

antihypertensive medications, can be mitigated (Srivastava, 1986). Because fatigue is such an obvious symptom burden in persons with ESRD and contributes quite significantly to overall quality of life, it warrants special consideration as a separate variable in the symptom domain of the revised Wilson and Cleary model (Ferrans et al., 2005).

Another symptom worth exploring in more depth is anxiety. Although 38% of persons on hemodialysis report anxiety (Murtagh et al., 2007), it has not been addressed in any studies involving quality of life in persons with ESRD. Measuring anxiety as a separate variable will contribute new knowledge regarding the influence of anxiety on overall quality of life for persons with ESRD.

Although anxiety and depression are often correlated, depression has been addressed in much greater depth in the quality of life literature for persons with ESRD. Depression is present in approximately 28% of persons with ESRD (Drayer et al., 2006; Murtagh et al., 2007; Weisbord et al., 2005), and as much as 61% in older dialysis patients (Tyrrell et al., 2005). Unfortunately, it is often not diagnosed in this population because the symptoms associated with depression mimic many of the symptoms prevalent in the hemodialysis population, such as fatigue, sleeping problems, and decreased appetite. However, the presence of depression has been associated with a decreased quality of life (Drayer et al., 2006; Patel et al., 2002; Walters, Hays, Spritzer, Fridman, & Carter, 2002) and a fourfold risk of death (Drayer et al., 2006). Understanding the individual contribution of depression and anxiety to quality of life is needed. Measuring each as a separate variable, in addition to their contribution to overall

symptom burden, will provide greater insight into symptoms and the influence of symptoms on quality of life.

Functional Status

Functional status is defined in various ways, but usually refers to the ability to perform certain tasks (Wilson & Cleary, 1995). These tasks may be physical, social, psychological, or role-related (Ferrans et al., 2005). Thomas-Hawkins (2004) defines functional status as the “ability to perform and the actual performance of daily activities” (p. 687). This definition includes both activities of daily living (ADL), such as dressing, eating, and hygiene; and instrumental activities of daily living (IADL), such as shopping, housekeeping, and transportation. In addition, the definition includes both what persons are capable of doing, and what they actually do, as these are different dimensions of functioning (Thomas-Hawkins, 2004).

Physical functioning includes four dimensions: functional capacity (maximum capacity to perform a specific task), functional performance (day-to-day activities), functional capacity utilization (percentage of functional capacity that is used day to day), and functional reserve (the difference between capacity utilization and functional capacity) (Leidy, 1994). Functional capacity is an intense way to measure function by requiring physical movement to the point of exhaustion. It works best for measuring one specific task, versus determining a global understanding of physical functioning. It is usually not appropriate for frail populations. No instruments have been developed for measuring functional capacity utilization or functional reserve (Leidy, 1994). Functional performance, which measures day-to-day activities, is an appropriate measure for persons

with ESRD to determine functional status. This conceptualization of functional status is an important component of what persons with ESRD include in their descriptions of quality of life (Thomas-Hawkins, 2004).

Physical functioning is often limited in persons with ESRD, usually due to symptoms or treatment regimen, and not renal failure itself (Painter, Stewart, & Carey, 1999). The exercise capacity of persons on dialysis is half that of the normal population (Curtin et al., 1999). In addition, renal patients face progressive debilitation and deconditioning, and most can not do more than attend to activities of daily living (Curtin et al., 1999). Further, older persons on dialysis have even lower physical functioning than their younger counterparts (Thomas-Hawkins, 2000).

Functional status is predictive of death in all populations, including persons with ESRD (Curtin et al., 1999). In a recent pilot study which looked at predictors of end of life during multiple hospitalizations in persons with ESRD, two predictors showed a significant change from the admission prior to death and the death admission (Kring & Crane, 2007). One variable was a measure of function and the other a measure of pressure ulcer risk, which included many functional indicators. These functional variables were more predictive of death than the physiological variables, including mean arterial pressure, pulse, temperature, weight, albumin, hemoglobin, and HgbA1c.

Functional status is modifiable, and persons who manage to maintain independent function have reported a higher quality of life (Molzahn, 2006). One study found that both an independent home exercise program and an in-center cycling program increased physical functioning and the physical component scale of the SF-36 (Painter et al., 2000).

Although physical functioning is an important domain within quality of life, most quality of life studies involving persons with ESRD did not measure function as a separate variable from quality of life. In fact, the use of the SF-36, often referred to as a health-related quality of life scale, is also frequently referred to as a measure of functional status—both physical and mental. Therefore, for many researchers, health-related quality of life and functional status are synonymous. Those studies that did measure physical function as a separate variable to correlate with quality of life used the Karnofsky Performance Scale (KPS) (Laws et al., 2000; Patel et al., 2002). This scale is commonly used within the dialysis population and some dialysis centers routinely complete the KPS on all patients. The KPS measures functional impairment related to disease progression and the amount of assistance or medical care needed to manage the disease process (Mor, Laliberte, Morris, & Wiemann, 1984). It provides an 11-point scale of function, with 100% indicative of full functioning and no evidence of disease; and 0% indicative of death. The KPS has since been updated to include more descriptors for classifying function according to ambulation, activity, evidence of disease, self-care, intake, and consciousness, and deleting references to hospitalization given many patients' desire to be cared for at home. This updated tool is known as the Palliative Performance Scale (PPS) (Anderson, Downing, Hill, Casorso, & Lerch, 1996). The PPS has not been used in the renal population. Therefore, research is needed which uses the more up-to-date PPS with the ESRD population as a measure of function. In addition, research is needed which examines the impact of physical functioning as a separate variable on quality of life in persons with ESRD, especially with a tool designed to measure ADL and IADL.

General Health Perceptions

General health perception is a representation of all health concepts together, plus any not specifically captured in another variable or instrument (Wilson & Cleary, 1995). It is individualized, completely subjective, and based on a concept first articulated by Campbell, Converse, and Rodgers (1976) which determined overall satisfaction with life using a single measure. It is still most commonly measured with one global question using a Likert-type scale to measure satisfaction with health (Ferrans et al., 2005). Including general health perception in a conceptual model of quality of life allows for additional subjective input which summarizes not only the biological function, symptoms, and functional status, but also incorporates characteristics of the individual, characteristics of the environment, and other non-identified antecedents of quality of life. It may help explain a portion of quality of life that other instruments are unable to capture because the construct “quality of life” is so complex.

Many health-related quality of life instruments include a question regarding general health perception, including the SF-36. However, the vast majority of studies examining quality of life in persons with ESRD do not single out this variable for statistical analysis. One study reported the general health perception of persons with ESRD using Campbell’s Overall Life Satisfaction Item and correlated it with various nutritional statuses (Laws et al., 2000). The investigators reported that severely malnourished renal patients had significantly lower general health perceptions (and scored lower on other quality of life domains) than patients who were well nourished or

moderately malnourished. Unfortunately, regression analysis was not done to determine the contribution of this domain on overall quality of life.

In accordance with the revised Wilson and Cleary model of health-related quality of life (Ferrans et al., 2005), general health perception should be included in studies of quality of life. It is a frequently overlooked variable and including it as a separate variable in quality of life studies with persons with ESRD may help explain a subjective and individualized component of quality of life not captured by other instruments.

Characteristics of the Individual

Characteristics of the individual are demographic, developmental, psychological, and biological factors that influence health outcomes (Ferrans et al., 2005). They impact all antecedents of quality of life, thereby moderating their influence. For the proposed study, age, gender, and race/ ethnicity have been selected as important characteristics of the individual that may impact quality of life in persons with ESRD.

Age is often used to describe the sample in studies examining quality of life in persons with ESRD, and sometimes it is explored as an independent variable. In a study of dialysis persons over the age of 70, 15% were found to have a very poor quality of life, although the range of scores was large (Tyrrell et al., 2005). Most studies have found that older persons with ESRD have a decreased quality of life than younger persons with ESRD (Baiardi et al., 2002; Ferrans & Powers, 1993; Frank et al., 2003; Lopes et al., 2007; Walters et al., 2002). However, one study found that younger dialysis patients (aged 26-45) had a significantly lower quality of life than a 56-65 age group, and a 66 and older age group (Greene, 2005), as measured by the holistic Quality of Life Index-

Dialysis version. The sample was limited to African Americans on hemodialysis living in a metropolitan area, and thus the findings may be related to culture rather than age. A study of Brazilian hemodialysis patients also found that age was not associated with quality of life (Morsch et al., 2006), which is an interesting finding given that quality of life was measured with the SF-36. The investigators in both studies hypothesized that older persons were more accepting of decreased limitations than younger persons. Given these results, and the association of age with physical function (Thomas-Hawkins, 2000), further investigation is needed regarding the impact of age on quality of life in persons with ESRD.

A few studies have examined the influence of gender on quality of life in persons with ESRD, also with mixed results. Three studies have found no differences in quality of life between men and women (Baiardi et al., 2002; Ferrans & Powers, 1993; Kalantar-Zadeh et al., 2001). However, two of these studies used the SF-36 (Baiardi et al., 2002; Kalantar-Zadeh et al., 2001), which is not a holistic measure of quality of life. Conversely, one study which also used the SF-36 found that men reported a higher quality of life than women (Frank et al., 2003). Two studies found that women and men were different on various domains of quality of life. Lopes et al. (2007) found that women had significantly lower quality of life related to symptoms and problems, but higher quality of life related to social interaction and sexual function, as measured by the Kidney Disease Quality of Life- Short Form (KDQOL-SF), which uses the SF-36 as its core. Walters et al. (2002), using the same instrument, found that women had significantly lower quality of life related to physical functioning, pain, emotional well-

being, and energy/ fatigue, but higher quality of life related to sexual function. Again, the studies to date have not provided adequate information regarding the influence of gender on perception of quality of life. All of the ESRD studies reporting gender as an independent variable except one used the SF-36, or a version of it, to measure quality of life. Using a more holistic measure of quality of life may yield different results.

Examining race/ ethnicity as an individual characteristic is also important when studying quality of life in persons on dialysis. Again, the results in the ESRD population have been limited and mixed. One Israeli study divided participants into two groups—Asian/ African and European/ American (Frank et al., 2003), and found that Asian/ African patients reported a significantly greater decrease in quality of life over time. Two studies reported that African Americans had a higher quality of life than Whites (Lopes et al., 2003; Weisbord et al., 2003). However, three other studies found no differences in racial/ ethnic influences on quality of life (Bakewell et al., 2001; Ferrans & Powers, 1993; Morsch et al., 2006). Race is an important consideration in the ESRD population because the relative risk of ESRD for African Americans is 3.52 compared to Whites (Li, McAlpine, Liu, & Collins, 2004). Including race/ ethnicity in future studies will provide additional information regarding racial and ethnic perceptions of quality of life.

Age, gender, and race/ ethnicity are examples of characteristics of the individual in the revised Wilson and Cleary model (Ferrans et al., 2005). The current literature on quality of life in persons with ESRD is not clear on how these variables impact quality of life. There are varying results regarding outcomes, and often measures of health status

were used to quantify quality of life rather than a more holistic quality of life instrument. Thus, examining age, gender, and race/ethnicity using a holistic quality of life measure will add new knowledge regarding quality of life in persons with ESRD.

Characteristics of the Environment

The environment, which includes both social interactions as well as physical surroundings, influences one's perception of quality of life (Ferrans et al., 2005). Like the characteristics of the individual, characteristics of the environment impact all antecedents of quality of life. Therefore, characteristics of the environment are important to include in quality of life research. Studies with persons with ESRD have examined marital status, socioeconomic status, and time on hemodialysis as important environmental factors.

Marital status implies the presence or absence of a fulfilling human relationship with a supportive partner who can also be relied upon for assistance with activities of daily living. Both the emotional and practical aspects of a long term partnership have implications for quality of life. Quality of life studies involving persons with ESRD have had mixed results with regard to marital status. One study found that married persons with chronic kidney disease, both pre-dialysis and after dialysis initiation, had a significantly higher quality of life than non-married persons (Frank et al., 2003). Another study using a large international database of 9,526 persons with ESRD found that married patients had significantly *lower* scores for sexual function and effects of kidney disease on daily life (Lopes et al., 2007). The investigators did not provide a possible rationale for this finding. Two other studies found that marital status did not have a significant

effect on quality of life (Ferrans & Powers, 1993; Morsch et al., 2006). The study by Ferrans and Powers used a mailed survey to measure quality of life. This design may have been biased towards respondents with a higher quality of life who could independently complete the survey, or who had a spouse that could assist. Those not married and/or with a poorer quality of life may not have been as able to complete the survey. The study by Morsch et al. defined marital status as “living alone” or “living with someone.” This dichotomous definition of marital status may not have captured the emotional bond associated with a committed, marital relationship. Therefore, marital status warrants further investigation within the ESRD population as it relates to quality of life.

Socioeconomic status is another characteristic of the environment that may influence quality of life. Persons living below poverty levels are often not able to afford adequate housing, transportation, food, and medications that can positively impact quality of life. In addition, poverty is often associated with other environmental concerns such as polluted neighborhoods and substandard housing (Bullard, 2002). Studies that have examined the impact of socioeconomic status (SES) of the quality of life of persons with ESRD report varied results. One study found that SES was positively correlated with quality of life, explaining between 5.5% and 14.1% of the variation in quality of life dimensions (Sesso et al., 2003). Another study reported that unemployment was significantly correlated with quality of life, and lower income was associated with lower mental component scores of the SF-36 (Lopes et al., 2007). However, two other studies reported that SES was not significantly correlated with quality of life (Ferrans & Powers,

1993; Frank et al., 2003). Although Ferrans and Powers did not find a significant relationship between income and quality of life, they did report a significant relationship between employment status and quality of life. Frank et al. (2003) did not provide a possible explanation for the lack of correlation between quality of life and SES. However, their study used the SF-36 which may have been a limited measure of quality of life. Because most persons with ESRD qualify for Medicare benefits, they usually receive similar health care independent of SES status. Therefore, a quality of life measure would need to measure quality of life more holistically than the SF-36 to capture differences in quality of life. Consequently, more research is needed to understand the impact of SES on a holistic conceptualization of quality of life.

Time on dialysis is the final characteristic of the environment that is an important variable to examine in quality of life studies. Persons on hemodialysis often anecdotally report a honeymoon phase following the initiation of hemodialysis due to a reduction in uremic symptoms. However, over time, the illness trajectory of persons with ESRD is portrayed as periods of stability interspersed with downward progression of the disease (Jablonski, 2004). Thus, according to this conceptualization, persons who have been on hemodialysis for a long time will experience an overall reduction in health. In addition, the longer a person has been on hemodialysis, the longer he or she has been immersed within the dialysis clinic culture, a highly technical, medicalized environment. This clinical environment is a constant reminder of disease and infirmity. Few studies of quality of life and ESRD have included time on hemodialysis as an independent variable. Two studies found no correlation between time on dialysis and quality of life (Ferrans &

Powers, 1993; Jablonski, 2007). However, another study comparing quality of life at the onset of hemodialysis and one year later, found that patients who had been undergoing hemodialysis for more than a year reported a higher quality of life (Morsch et al., 2006). Likewise, Walters et al. (2002) found that persons who had been on hemodialysis for a longer period of time reported a higher quality of life than persons who were new to hemodialysis. Both studies used the SF-36 (Walters et al. used the KDQOL-36) to measure quality of life which may indicate an improvement in uremic symptoms rather than an improvement in overall quality of life. Further study is needed to understand how time on dialysis affects overall quality of life.

Marital status, SES, and time on dialysis are examples of characteristics of the environment in the revised Wilson and Cleary model (Ferrans et al., 2005). The findings of current studies with persons who have ESRD provide conflicting evidence of the impact of these variables on quality of life. As seen in many studies, the SF-36 was a commonly used instrument to measure quality of life, which is a better measure of health status than quality of life. Therefore, further research is needed as to which environmental characteristics most impact overall quality of life.

Summary

Many studies have examined quality of life in persons with ESRD. However, only two used a conceptual model that clearly delineated the antecedents of quality of life (Ferrans & Powers, 1993; Frank et al., 2003). Frank et al. used Wilson and Cleary's depiction of health-related quality of life and Ferrans and Powers used the domains identified from a factor analysis of their Quality of Life Index. No studies have been

published using the revised Wilson and Cleary model (Ferrans et al., 2005), which was expanded to include a more holistic conceptualization of quality of life. In addition, no studies have been done which comprehensively analyze biological function, symptoms, functional status, general health perceptions, and various characteristics of the individual and environment. A study by Frank et al. (2003) used the original Wilson and Cleary model and included all of the variables reviewed except functional status. However, they used the SF-36 to measure quality of life, not a holistic instrument. Studies which used a more holistic measure of quality of life (Bihl et al., 1988; Ferrans & Powers, 1993; Greene, 2005; Jablonski, 2007; Laws et al., 2000) did not articulate a holistic conceptual framework to guide their study variables, thus limiting the independent variables used to explain quality of life. Therefore, a study is needed to fill these gaps in knowledge.

Quality of life research with persons with ESRD has mainly focused on health-related quality of life, which might best be described as health status. This narrow conceptualization has left a gap in our understanding of quality of life for persons with ESRD and its influencing factors. Studies are needed that use a quality of life conceptual framework which incorporate important health-related factors, as well as individual and environmental characteristics which include a broad, holistic approach. Understanding quality of life through this holistic lens will add to our understanding of the quality of life for persons with ESRD.

CHAPTER III

METHODS

Design

This non-experimental research study employed a cross-sectional, correlational design to determine factors affecting quality of life in persons on hemodialysis. A cross-sectional design examines data at one point in time and is best used to describe the status of phenomena and/ or the relationships among phenomena (Polit & Beck, 2008). Data were collected one time from participants to describe their current level of quality of life, as well as factors affecting their quality of life. This design was appropriate because the study did not look at changes in quality of life over time.

A correlational design was also used. A correlational design examines interrelationships or associations among variables that cannot be manipulated (Polit & Beck, 2008). This approach was suitable for the study because none of the independent variables (biological function, symptoms, functional status, general health perceptions, age, gender, race/ ethnicity, time on dialysis, marital status, or socioeconomic status) could be logistically or ethically manipulated.

Setting

The data collection took place in a free-standing, outpatient dialysis clinic located in central North Carolina. This clinic is one of five dialysis centers operated by the same national, for-profit company located within the county. Among the five clinics, there are

over 500 persons on hemodialysis. The clinic used for data collection is the largest of the five, and currently has 157 persons regularly attending in-patient hemodialysis. The medical care at all the centers is managed by nephrologists working within the same private practice.

Sample

A convenience sampling design was used to obtain participants from the outpatient dialysis clinic. Inclusion criteria consisted of: (a) persons actively undergoing in-center hemodialysis, (b) on hemodialysis for at least three months, (c) at least 18 years of age or older, and (d) able to speak and understand the English language. Exclusion criteria consisted of: (a) a diagnosis of dementia or other condition which may impair the ability to answer questions, and (b) cognitive or medical changes occurring during the hemodialysis treatment that prevented the person from answering questions.

Eligible persons at the dialysis center were approached by the charge nurse regarding their interest in participating. A letter explaining the study was provided to each eligible, interested person. The letter briefly explained the purpose of the study and indicated the time involvement. The letter was written on a fifth grade reading level with 14-point font to assist with readability. All participants receiving a recruitment letter were approached by the investigator to answer questions and obtain consent. This process continued until an appropriate sample size was recruited. All participants were recruited from one dialysis center. This dialysis center is located in the center of a metropolitan area and serves persons of various socioeconomic statuses and races. Confining participants to one center minimized disruption to patient care and facilitated

the research process by limiting persons needed to assist the investigator. Although individuals typically attend the dialysis center closest to their home, it is expected that a representative sample from the county was obtained because each facility is very similar in ownership, policies and procedures, patient demographics, and local hospital and community resources.

A power analysis was conducted using nQuery Advisor software to determine the needed sample size to answer the research questions. For multiple linear regression, with a significance level of 0.05, 80% power, 15 predictor variables, and an estimated moderate effect size ($R^2 = 0.25$), 70 subjects were needed. A conservative R^2 was estimated from a study using the Quality of Life Index- Dialysis version with persons on hemodialysis, in which the R^2 was reported as 0.28 (Jablonski, 2007).

Human Subjects Protection

The study was approved by the Institutional Review Board (IRB) of The University of North Carolina at Greensboro. In addition, permission to conduct the study at the dialysis clinic was obtained from Fresenius Medical Care's Department of Clinical Studies according to corporate policy.

All participants were fully informed regarding the purpose of the study and expectations of participation. A written consent form was reviewed and signed by each participant prior to collecting data and each participant received a copy. The consent form was written at a fifth grade reading level and clearly stated that participation was completely voluntary, including a statement that withdrawal from the study was permitted at any time without negative consequences. In addition, a HIPAA form

required by the dialysis center was signed by each participant allowing access to medical records kept at the center.

Confidentiality was maintained on all data collection forms by using codes to identify participants instead of names, medical record numbers, social security numbers, or any other personal identifiers. A master list of participant names was kept separate from the data collection forms. This master list was used during the data collection period to ensure that persons were not recruited more than once. All data collection forms are kept in a locked file in the investigator's office separate from the master list. Computer files pertaining to the study only use participant codes as identifiers.

Instruments

Eight instruments were used to collect data: (a) the Dialysis Demographic Form, (b) the Dialysis Symptom Index, (c) the Hospital Anxiety and Depression Scale, (d) a Fatigue Visual Analog Scale, (e) the Inventory of Functional Status- Dialysis, (f) the Palliative Performance Scale, (g) the Global Question of General Health Perception, and (h) the Quality of Life Index- Dialysis Version.

Dialysis Demographic Form. The Dialysis Demographic Form, an investigator-designed form, was used to collect information not captured on the other instruments (see Appendix A). It included characteristics of the individual (age, gender, and race), characteristics of the environment (time on hemodialysis, marital status, and socioeconomic status), and most recent serum albumin and hemoglobin levels. Section A of the Dialysis Demographic Form was completed by the investigator, and included information that could be extracted from the medical records kept at the dialysis center.

Section B of the Dialysis Demographic Form included questions to be asked of the participant, such as race/ ethnicity, marital status, and socioeconomic status (SES). These variables are not usually in the medical record or may not be accurate. To determine SES, the participant was asked to examine a chart indicating the number of people in the household, cross-referenced with household incomes indicating poverty. This chart reflects the poverty guidelines updated periodically in the Federal Register by the U.S. Department of Health and Human Services (2007) under the authority of 42 U.S.C. 9902(2). The participant was asked, “Is your household income more than the indicated amount for the number of people in your home?”

Dialysis Symptom Index. Most studies that have explored symptoms experienced by persons on dialysis have used either a general symptom scale imbedded within a larger instrument, such as the SF-36 (Thomas-Hawkins, 2000; Weisbord et al., 2003) or the investigators generated their own tool of dialysis symptoms for the purposes of the study (Curtin, Bultman, et al., 2002; Jablonski, 2007; Merkus et al., 1999). The problem with using a general symptom scale is that the unique symptoms experienced by persons on dialysis are often not addressed. The problem with investigator-generated tools for specific studies is that they are often not accessible to other researchers, vary considerably in the number and dimensions of symptoms measured, and may not have been subjected to rigorous reliability and validity testing.

The Dialysis Symptom Index (DSI) is a comprehensive instrument which measures 30 common physical and emotional symptoms experienced by persons on hemodialysis, and the severity/ frequency of those symptoms (see Appendix B)

(Weisbord et al., 2004). The participant was asked if a symptom was experienced during the past week. If yes, the participant was asked to what degree it was bothersome on a five-point scale, with 1 = not at all, and 5 = very much. The responses on the severity dimension were added together for a total symptom severity score.

The DSI was created in four phases. During phase one, general symptom indices that had been used in previous research with persons on hemodialysis were identified and the symptoms extracted for analysis. These indices included four subscales within health-related quality of life questionnaires, one pre-hemodialysis symptom index, and a cancer symptom index. During phase two, three focus groups were held to determine symptoms experienced by persons on dialysis—two with persons on hemodialysis, and one with renal providers. These focus groups were audiotaped and transcribed verbatim. Forty-four symptoms were identified from these sessions. After the first two phases, a total of 75 symptoms were identified. Each symptom was tallied for the number of times it appeared in symptom indices or focus group transcripts. Any symptom appearing four or more times was included in the initial DSI. This cut-point was a subjective decision by the developers of the tool. Forty-seven symptoms met this criterion. Several symptoms overlapped and were combined, such as “lack of strength” and “weakness.” This process resulted in 34 separate symptoms. During phase three, eight content experts completed content validity surveys. Four items were discarded and seven were reworded which resulted in a 30-item instrument. Convergent evidence for construct validity was later obtained for this new symptom instrument by significantly correlating symptom burden with the related construct, quality of life (Weisbord et al., 2005).

During the final phase of instrument development, test-retest reliability was conducted with 20 persons on hemodialysis, 4-7 days apart. The percent total agreement was high ($M = 0.80$, $SD = 0.09$). Most items had acceptable kappa statistics, except for three. Acceptable kappa levels are generally agreed to be 0.60 or higher (Polit & Beck, 2008). Diarrhea ($\kappa = 0.06$) and dizziness/ lightheadedness ($\kappa = 0.12$) are both transient symptoms and the low kappa values were expected. The researchers were unsure why the third symptom, ability to concentrate ($\kappa = 0.12$), also received a low kappa value. The overall kappa statistic for the entire tool was 0.48, $SD = 0.22$, due to the transient symptoms.

Hospital Anxiety and Depression Scale. The Hospital Anxiety and Depression Scale (HADS) (see Appendix C) was developed as a short tool to identify patients at risk for two common psychological disorders—anxiety and depression (Zigmond & Snaith, 1983). Since its introduction, it has been used in over 745 published papers (Bjelland, Dahl, Haug, & Neckelmann, 2002). The HADS has 14 items—seven related to anxiety and seven related to depression. Each item is a statement to which respondents choose the degree to which the statement is true for them on a four-point Likert type scale, from 0-3, with 0 representing no symptoms, and 3 representing the clear presence of symptoms related to anxiety or depression. The two subscales (HADS-A and HADS-D) are summed separately and may also be added together for a total score. The cut-off score for determining the presence of anxiety or depression is eight for each subscale (Bjelland et al., 2002).

Concurrent validity has been reported in several studies. When the HADS was administered to 50 people who had been previously diagnosed with anxiety or depression, the cut-off points were the same for each subscale, with only one false positive for each subscale (Zigmond & Snaith, 1983). In a literature review of the HADS, Bjelland et al. (2002) found that six studies reported positive correlations between the HADS-D and Beck's Depression Inventory which ranged from 0.62-0.73. In two other studies, correlations between the HADS-A and the Clinical Anxiety Scale were 0.69 and 0.75 (Bjelland et al., 2002). In addition, correlations between the HADS-A and Spielberger's State-Trait Anxiety Inventory ranged from 0.64-0.81 (Bjelland et al., 2002).

Construct validity was tested by the authors of the HADS (Zigmond & Snaith, 1983). Patients were asked to complete the HADS and a clinical psychologist also completed the HADS for each patient following a clinical interview. Patients who were determined by the psychologist to be anxious, had scores that correlated well with the HADS-A ($r = 0.54$) but not the HADS-D ($r = 0.08$). Similarly, patients who were determined to be depressed by the psychologist, had scores that correlated well with the HADS-D ($r = 0.79$) but not the HADS-A ($r = 0.19$). Although patients often have dimensions of both depression and anxiety, the authors demonstrated that they are separate and different aspects of mood disorder.

Factorial validity was documented by Bjelland et al. (2002) who found that of 19 studies using the HADS, 11 achieved a 2-factor structure that was stable across different clinical populations and genders. In addition, 21 studies using the HADS had a mean

Pearson correlation coefficient between the two subscales of 0.56, demonstrating that the two subscales are related but different constructs (Bjelland et al., 2002).

The authors of the HADS evaluated the internal consistency of both subscales by correlating each item with its corresponding subscale score (Zigmond & Snaith, 1983). Correlations for the HADS-A ranged from 0.41-0.76 ($p < 0.01$), and for the HADS-D, correlations ranged from 0.30-0.60 ($p = 0.02$). Since then, internal consistency has been reported in the literature to be much higher. In an analysis of 15 studies using the HADS, the anxiety subscale correlations ranged from 0.68-0.93, and the depression subscale correlations ranged from 0.67-0.90 (Bjelland et al., 2002).

Fatigue Visual Analog Scale. Visual analog scales (VAS) are used to measure subjective experiences (Polit & Beck, 2008). They usually consist of a 100 mm line anchored at both ends with perpendicular lines indicating extreme instances of the concept being measured. The participant is asked to mark a point on the line indicating their subjective experience of the concept. A measurement is then taken from one end of the scale to the participant's mark, providing a score for that item.

A VAS was used to measure fatigue in this study (see Appendix D). The left VAS anchor indicated “no fatigue” and the right anchor indicated “severe fatigue.” Measurements were made from the “no fatigue” anchor to the participant's mark. Thus, the higher the number, the worse the fatigue. Participants with no fatigue were asked to circle the left anchor. Participants with severe fatigue were instructed to circle the right anchor. It is a quick, simple tool to complete and has correlated well with longer instruments, including Belza's Multi-dimensional Assessment of Fatigue scale ($r = 0.80$),

the vitality subscale from the SF-36 ($r = 0.71$), and the Brief Fatigue Inventory ($r = 0.76$) (Wolfe, 2004).

Inventory of Functional Status- Dialysis. The Inventory of Functional Status-Dialysis (IFS-D) (see Appendix E) was developed and tested specifically for persons on dialysis (Thomas-Hawkins, 2004). It is derived from the Roy Adaptation Model (RAM) and has 17 activities divided into three subscales—personal care activities, household activities, and social/ community activities—which align with the primary, secondary and tertiary role functions of the RAM. This scale measures the actual activities that persons engage in, not the activities that they *can* engage in. The participant must rate each activity in the subscales according to the degree of participation in a typical week in the past month on a four-point scale: 1 = did not do, 2 = did with a lot of help, 3 = did with some help, 4 = did by myself. Points are given for each activity and averaged to determine an overall functional status score, ranging from 1.00 to 4.00. A higher score indicates a higher level of functioning.

Content validity is supported through the tool's use of items originating from the Comprehensive Inventory of Functioning, a RAM-based instrument. In addition, items were also developed from clinical observations of dialysis patients as well as suggestions from dialysis patients. Fifteen dialysis patients reviewed the tool, and Popham's average congruency procedure was used to further establish content validity. This procedure measures the average percent of agreement by content validity judges who must decide if the questionnaire items measure the concept being studied (Thomas-Hawkins, 2004).

Eight items were deleted during this process, and the final tool had a content validity average congruency of 90%.

The IFS-D has also undergone construct validity testing (Thomas-Hawkins, 2004). Confirmatory factor analysis determined that each item was significantly related to its respective subscale latent variable. Loadings by subscale ranged from 0.44-0.84 and the relative $\chi^2 = 2.0$, indicating a good fit of the measurement model to the data. Correlation coefficients ranged from 0.28-0.54 demonstrating that the scales were related but independent. Correlations were also conducted between the IFS-D and the Karnofsky Performance Status scale, a generic measure of functional ability, and the physical, role, and social function subscales of the SF-36. Correlations ranged between 0.27-0.55 indicating that the IFS-D was measuring a similar but distinct concept. Some distinctions include the fact that the IFS-D measures actual participation in activities, the KPS measures functional ability, and the SF-36 measures the impact of health on functioning. In a contrasted groups approach to determining construct validity, the IFS-D was given to both older and younger patients on dialysis with the expectation that older persons would report a lower level of actual function than younger persons. As expected, a significant, negative correlation was found ($r = -0.49, p < 0.01$) (Thomas-Hawkins, 2004).

The IFS-D also has good reliability statistics. Alpha reliability for the total scale score was 0.88, and subscale reliabilities ranged from 0.75-0.85 (Thomas-Hawkins, 2004). Coefficients of 0.70 and above are considered adequate indicators of internal consistency (Polit & Beck, 2008).

Palliative Performance Scale. The Palliative Performance Scale (PPS) (Anderson et al., 1996), a modification of the Karnofsky Performance Scale (KPS), measures the decline in function seen in terminal patients as they approach death (see Appendix F). The index ranges from 100% (normal, no evidence of disease) to 0% (deceased). The scale progresses in 10% increments within these two anchors to describe overall level of function. Persons are classified against five categories: ambulation, activity/ evidence of disease, self-care, intake, and level of consciousness according to descriptors for each percentage from 0-100. In the event that someone does not align at the same percentage across the categories, the categories on the left of the scale carry more weight and should take precedence in determining an overall score. The improvements made to the KPS which resulted in the PPS include more specific descriptions of the five categories for classifying functional decline, as well as the deletion of requirements for hospitalization, as patients often have other non-hospital options at the end of life.

The PPS was developed for prognostication purposes, research, and program planning related to palliative care needs (Anderson et al., 1996). Its predecessor, the KPS, has been used as a measure of function in studies involving persons with ESRD (Laws et al., 2000; Patel et al., 2002). Although the more up-to-date PPS has not been used in studies involving persons with ESRD, it may prove to be a useful measure for determining functional decline in this population as it relates to quality of life. For future studies, it may possibly help identify stages along the chronic illness trajectory, including the terminal phase.

Because the PPS was designed to predict death, evidence of construct validity has focused on its prognostic properties. In the original testing of the instrument, the authors found that patients with a PPS score of 10% had an average time to death of 1.88 days, 20% had 2.62 days, 30% had 6.7 days, 40% had 10.3 days, and 50% had 13.87 days (Anderson et al., 1996). Since this study, others have also validated its ability to predict death. Morita, Tsunoda, Inoue, and Chihara (1999) found that patients with a PPS score between 30-50% survived significantly longer than patients with a PPS score of 10-20%, and patients with a PPS of 60-100% survived significantly longer than all others. Virik and Glare (2002) found that 90% of patients with a PPS score of 10% when in the hospital did not survive the admission, while every patient with a PPS score of 70% or above did survive. Survival analysis verified that survival curves were longer as the PPS score increased. Lau, Downing, Lesperance, Shaw, and Kuziemy (2006) also verified that PPS scores 10% through 50% had distinct survival curves. Harrold et al. (2005) found that the PPS was a strong predictor of mortality ($p < 0.001$) in patients with cancer and non-cancer diagnoses, including ESRD. Kring and Crane (2007) found that in a pilot study examining the ability of various demographic, physiological, and functional variables to predict death in hospitalized persons with ESRD, the PPS was significantly lower at the death admission than the admission immediately prior to the death admission. Convergent validity was established by correlating the PPS with its predecessor, the KPS ($r = 0.94$) (Morita et al., 1999).

Reliability has not been as well documented as validity. However, one study reported good interrater reliability with quadratically weighted kappa = 0.67 ($p < 0.001$)

(Harrold et al., 2005). A kappa value of 0.60 is considered minimally acceptable (Polit & Beck, 2008).

General Health Perceptions. General health perception (see Appendix G) is often measured with one global question that allows the individual to synthesize all objective and subjective experiences regarding their personal health (Wilson & Cleary, 1995). This factor was measured by one item, “How would you rate your health on a scale from 1 to 10, with 1 = poor and 10 = excellent?” as recommended by Ferrans et al. (2005).

Quality of Life Index- Dialysis. The Quality of Life Index- Dialysis Version III (QLI-D) (see Appendix H) is a subjective, self-report measure comprised of 34 pairs of questions (Ferrans & Powers, 1985). Thirty-two items make up the core version of the QLI and assess health care, physical health and functioning, occupation, education, leisure, the future, peace of mind, personal faith, life goals, personal appearance, self-acceptance, general happiness, and general satisfaction. Two additional questions are included in the QLI-D which assess life changes due to kidney failure and the possibility of a kidney transplant. For each pair of questions, the first item asks the degree to which individuals are *satisfied* with a certain aspect of their life, and is measured on a 6-point Likert-type scale with 1 = very dissatisfied, and 6 = very satisfied. The second item asks the level of *importance* of that aspect of their life, and is also measured on a 6-point Likert-type scale with 1 = very unimportant, and 6 = very important. The satisfaction scores are recoded and weighted according to the importance scores to determine an overall quality of life score. Possible range for the final score is 0 to 30, with higher scores indicating a higher overall quality of life. Thus, the QLI-D accommodates the

relative significance of every item, making it a value-specific and individualized instrument (Ferrans, 1996). The instrument's structure flows directly from the author's definition of quality of life which states that "a person's sense of well-being . . . stems from satisfaction or dissatisfaction with the areas of life that are important to him/ her" (Ferrans, 1996, p. 296).

The QLI-D was an ideal instrument for this study for three important reasons. First, it is a self-report measure. Using a self-report measure for quality of life is important because nurses often rate patients' quality of life lower than patients rate themselves, and physicians tend to rate patients' quality of life higher than patients do (Phillips et al., 2001). Second, it is specific to persons on dialysis. Global measures of quality of life may not include the unique life style changes required of persons with kidney disease, thereby overestimating perceived quality of life (Phillips et al., 2001). Finally, the QLI-D is a holistic measure of quality of life. It includes not only a health and functioning domain, but also psychological/ spiritual, socioeconomic, and family domains (Ferrans, 1996). The scale's multi-dimensionality produces separate subscale scores which allow further statistical analysis regarding the effect of individual and combined factors on various domains of quality of life. The impact of health on the various domains is not included in the scale (as is the case with the SF-36), thus making it an overall quality of life index, not a "health-related" quality of life index nor a "health status" index.

Content validity for the QLI-D was established by constructing items based on a comprehensive literature review related to quality of life, as well as analyzing the

responses of persons on dialysis to open-ended questions regarding quality of life (Ferrans & Powers, 1985; Ferrans & Powers, 1993). Construct validity was supported through a factor analysis which revealed four separate domains explaining 91% of the total variance in quality of life (Ferrans & Powers, 1993). These domains include health and functioning, socioeconomic, psychological/ spiritual, and family. In addition, when participants were divided into high and low socioeconomic groups, a significant difference was found in the socioeconomic subscale (Ferrans & Powers, 1992). When participants were divided into groups based on severity of symptoms, those with less pain, less depression, or who were coping better with stress had significantly higher quality of life scores (Ferrans, 1990). To support convergent validity, the QLI (generic version) has been correlated with a single-item life satisfaction assessment across several studies. This single-item measure was developed from the work of Campbell, Converse, and Rodgers (1976) and asks how generally satisfied an individual is with life. Correlations between the QLI and life satisfaction scores range from 0.61-0.93 across seven studies (Ferrans, 2006). The correlation between the QLI-D and life satisfaction was 0.65 with persons on dialysis (Ferrans & Powers, 1992).

Reliability of the QLI has been well established. In the initial testing of the generic instrument, Cronbach's alpha was 0.93 for graduate students, and 0.90 for dialysis patients (Ferrans & Powers, 1985). Test-retest statistics were 0.87 after two weeks for graduate students, and 0.81 after one month for dialysis patients (Ferrans & Powers, 1985). Across 48 studies involving persons of varying diagnoses, Cronbach's alpha has ranged from 0.73 - 0.99, and 0.88 - 0.93 for persons on dialysis (Ferrans, 2006).

Procedures

The principal investigator (PI) educated the charge nurse from the participating dialysis center regarding the study purpose and data collection methods. The charge nurse approached all eligible persons regarding the study to obtain an initial determination of interest. The charge nurse gave all interested participants a letter from the PI describing the study in more detail, including specific subject requirements. This letter was written at a fifth grade reading level in 14-point font to assist with readability. The PI or a Research Assistant (RA) approached all eligible, interested participants during a routine dialysis session to answer questions and obtain written consent, including a HIPAA waiver required by the dialysis center.

The PI trained one RA to assist with data collection. The RA was a registered nurse familiar with care of persons on dialysis. Training included screening for eligibility, human subject protection, how to complete data instruments, data collection procedures to maintain reliability, data management to maintain integrity and confidentiality, and managing cognitive changes or fatigue during data collection. The RA observed two simulated data collection sessions by the PI, and then the PI and RA simultaneously recorded data on each instrument with two separate simulated subjects. Simultaneous data collection continued in this controlled environment until an interrater reliability score of >0.90 was obtained on each measure. The PI collected data on 37% of the participants, and the RA collected data on the remaining 63%.

Participants completed the study instruments during a routine dialysis session. Data collection did not occur until the person had been on dialysis for at least 60 minutes.

This lag time prevented data collection during a potentially unstable time of hemodialysis when fluid and electrolyte shifts are greatest and individuals are prone to cognitive changes. Participants were asked to complete eight instruments: (a) the Dialysis Demographic Form—part B, (b) the Dialysis Symptom Index, (c) the Hospital Anxiety and Depression Scale, (d) a Fatigue VAS, (e) the Inventory of Functional Status—Dialysis, (f) the Palliative Performance Scale, (g) the General Health Perception Survey, and (h) the Quality of Life Index—Dialysis version III. The instruments were read to the participants in an interview fashion. Response scales, but not the questions, were given to the participants to refer to during the interview. This strategy eliminated bias due to literacy levels, allowed the participant to ask clarifying questions during data collection, and provided a visual cue for accurate responses. Participants who were willing to participate but were uncomfortable with the interview method completed the study instruments independently if deemed cognitively intact by regular dialysis personnel. It was anticipated that completion of all eight instruments would take approximately 60 minutes, however the average completion time anecdotally was reported to be closer to 30 minutes. If participants were unable to complete all instruments during one session, data collection continued at the next scheduled dialysis session, or within one week. Only one participant completed the instruments in two separate sessions. The instruments were administered in rotating order to decrease bias due to response fatigue.

Each study instrument was completed in its original format, except for the PPS. The PPS is usually completed by a health care provider in collaboration with the patient or family. It involves some subjectivity on the part of the person computing the final

percentage. For this reason, the PPS was reformatted during data collection to facilitate ease in selecting responses (see Appendix F). Each question had only one best response which was recorded on the reformatted tool by either the PI or RA. At a later time, these responses were transferred by the PI onto the original PPS form and a percentage determined by the PI. No other person was involved in calculation of the PPS percentage.

Participants received a thank you letter from the PI and a ten dollar bill immediately following completion of all instruments as a token of appreciation for their time and willingness to share their experiences.

Data Analyses Plan

Descriptive statistics were calculated for each variable. Mean, standard deviation, range, skewness and kurtosis were determined for all interval-level variables. Proportions were determined for each nominal-level variable. All interval-level data that was not normally distributed was transformed to meet assumptions before applying statistical tests.

Instrument testing was done prior to other data analyses. Scores were calculated for the Dialysis Symptoms Index, Hospital Anxiety and Depression Scale, Fatigue Visual Analog Scale, Inventory of Functional Status- Dialysis, Palliative Performance Scale, and Quality of Life Index—Dialysis version III. Cronbach's alpha was calculated for each instrument.

Data analyses for specific aims. Data analyses for each specific aim and research question are outlined below.

Specific Aim #1: Describe the quality of life in persons with ESRD.

Q1: What is the quality of life in persons with ESRD?

To determine the quality of life in persons with ESRD, the total score of the Quality of Life Index- Dialysis version III was calculated for each participant. Syntax developed for SPSS by the index's author was used to recode and weight each item according to importance ratings. The mean, standard deviation, minimum, and maximum for the total QLI-D were calculated. In addition, subscale scores (health and functioning, socioeconomic, psychological/ spiritual, and family) were also calculated.

Specific Aim #2: Examine factors that may affect quality of life in persons with ESRD.

Q2: Do biological function (serum albumin and serum hemoglobin), symptoms (dialysis symptoms, anxiety, depression, and fatigue), functional status, and general health perception explain quality of life in persons with ESRD?

All independent variables were correlated with each other and checked for multicollinearity. In the event that two variables correlated at 0.85 or higher, one variable would be eliminated from the multiple regression analysis or separate models would be created. In addition, the tolerance level and variance inflation factor of all independent variables were calculated to further determine multicollinearity when all variables were examined together. A tolerance value less than 0.10 and a variance inflation factor greater than 10 were used to identify multicollinearity for possible elimination of variables (Mertler & Vannatta, 2002).

Extreme outliers can have an unacceptable impact on a regression solution. Therefore, frequency distributions were run for each variable and examined for outliers. In addition, multivariate outliers were detected through standardized residual values greater than 3.0 or less than -3.0. Outliers would be rescored, deleted, or separate regression models would be created.

Next, all variables were checked for assumptions related to multiple regression—multivariate normality, linearity, and homoscedasticity—by examining standardized residual scatterplots. Scatterplots should reveal a rectangular form distributed equally along the center line. Violations of any of the assumptions for multiple regression will reveal a different scatterplot shape. In the event that any assumptions were violated, data would be transformed in an attempt to stabilize the variance and achieve linearity and normality (Polit, 1996).

All predictor variables were entered simultaneously into a multiple regression model to determine how well the main health-related variables—biological function, symptoms, functional status, and general health perception—explained overall quality of life. Statistical significance for each variable was set at $\alpha = 0.05$, but the overall model was set at $\alpha = 0.01$. This higher significance level for the overall model was chosen to prevent a Type I error due to multiple analyses. Because three separate analyses using overall quality of life as the dependent variable were conducted, a Bonferroni correction was applied to the significance level (Polit, 1996), yielding the higher alpha.

One point of possible concern should be addressed at this point. Hemoglobin levels can vary according to gender differences and therefore are sometimes reported as normal or abnormal according to gender-specific and/ or menopausal guidelines (Williams, Crane, & Kring, 2007). However, these differences are not prevalent in persons with ESRD because amenorrhea is common for women of child bearing age, and pregnancy is very rare (Candela & Parker, 2006). Recent studies examining hemoglobin and hematocrit levels and their effect on quality of life have kept the serum values as continuous level variables, without adjusting for gender differences (Baiardi et al., 2002; Lopes et al., 2007; Morsch et al., 2006; Patel et al., 2002). To explore the issue of hemoglobin and gender differences, analysis for the proposed study included a *t*-test for differences in the mean hemoglobin levels between men and women. If no significant differences existed, the continuous level variable would be included in the regression analysis. If differences were present, the hemoglobin levels would be recoded as “normal” or “abnormal” according to the National Kidney Foundation guidelines for anemia, which takes menopausal status into consideration (National Kidney Foundation, 2007). According to these guidelines, a normal hemoglobin for men and post-menopausal women is 12.5 g/ dl or greater, and for non-menopausal women a normal hemoglobin is 11.0 or greater. If recoded, hemoglobin would be entered into the regression equation as a dichotomous dummy variable.

Q3: Do biological function (serum albumin and serum hemoglobin), symptoms (dialysis symptoms, anxiety, depression, and fatigue), functional status, general health perception, characteristics of the individual (age, gender, race/ ethnicity), and

characteristics of the environment (time on dialysis, marital status, and SES status) explain quality of life in persons with ESRD?

The statistical analysis for this question was similar to the analysis done for question two. Data were checked for multicollinearity, multivariate normality, linearity, homoscedasticity, and outliers. *All* predictor variables were entered simultaneously into a multiple regression model to determine how well the 15 variables explained overall quality of life. Statistical significance for each variable was set at $\alpha = 0.05$ and the overall model was set at $\alpha = .01$.

Q4: Do biological function (serum albumin and serum hemoglobin), symptoms (dialysis symptoms, anxiety, depression, and fatigue), functional status, general health perception, characteristics of the individual (age, gender, race/ ethnicity), and characteristics of the environment (time on dialysis, marital status, and SES status) explain *dimensions* of quality of life (health and functioning, socioeconomic, psychological/ spiritual, and family) in persons with ESRD?

The statistical analysis for this question was also similar to the analysis done for question two. Data were checked for multicollinearity, multivariate normality, linearity, homoscedasticity, and outliers. All predictor variables were entered simultaneously into a multiple regression model to determine how well the 15 variables explain each of the four domains of quality of life. Four separate models were run, one for each domain. Statistical significance for each variable and the overall model was set at $\alpha = .05$.

Q5: When controlling for characteristics of the individual (age, gender, and race) and characteristics of the environment (marital status, socioeconomic status, and time on

hemodialysis), do biological function (serum albumin and serum hemoglobin), symptoms (dialysis symptoms, anxiety, depression, and fatigue), functional status, and general health perception explain quality of life in persons with ESRD?

For this final analysis, data were again checked for multicollinearity, multivariate normality, linearity, homoscedasticity, and outliers. Characteristics of the individual and characteristics of the environment were entered into the multiple regression model as the first block. Then the other predictor variables were entered together as the second block. This analysis determined the specific amount of variance that health-related variables have on overall quality of life above and beyond what was explained by characteristics of the individual and characteristics of the environment (Mertler & Vannatta, 2002).

Limitations

Several limitations to this cross-sectional study design are acknowledged. Because persons on dialysis typically spend 12 hours or more per week undergoing this therapy at a local community clinic, recruitment was most likely enhanced by allowing them to participate during a regularly scheduled dialysis treatment. However, hemodialysis can cause dramatic swings in blood pressure and electrolytes. Thus, they may not have felt their best while answering questions related to their health and overall feelings of well-being. In addition, intra-dialytic cognitive changes, including decreased concentration and memory, have been reported (Griva et al., 2003). These changes are often transient and care was taken to ensure that the person had stabilized after dialysis initiation before participating in the study and that ample time was provided to respond to questions. A convenience sample from one county was used for the study. Persons who

agreed to participate may be different from those who declined. In addition, participants from this county may be different from dialysis persons in other counties, as well as other parts of the country. Thus, the sampling technique may limit external validity. In addition, the cross-sectional study design isolated participants' experiences to one point in time. This approach may misrepresent the dynamic nature of quality of life and its influencing factors.

Summary

A cross-sectional, correlational non-experimental study was conducted to determine factors affecting quality of life in persons on hemodialysis. A targeted convenience sample of at least 70 persons undergoing hemodialysis at an outpatient dialysis center located within one city in central North Carolina was used. The research study was approved by the IRB of The University of North Carolina at Greensboro, as well as Fresenius Medical Care's Department of Clinical Studies. Eight instruments were administered by the PI and one RA to participants while they were undergoing routine dialysis treatments. Data analysis included descriptive statistics, as well as various multiple regression models, to determine the influence of 15 predictor variables on quality of life, according to the revised Wilson and Cleary model of quality of life (Ferrans et al., 2005).

CHAPTER IV

RESULTS

This chapter will describe the results of the statistical analyses. A description of the final sample size is followed by an examination of study data, outcomes of instrument testing, demographic data, and an analysis of each separate research question. In addition to the planned tests, several additional models were explored based on initial findings.

Sample

All the patients (N = 157) at the selected dialysis center received a recruitment letter from the center's charge nurse. Eighty-five persons were approached by the Principal Investigator (PI) or Research Assistant (RA) to participate. Persons were approached if they were 60 minutes into their dialysis treatment, had at least 60 minutes remaining, and were awake. Twelve persons did not participate: (a) seven declined with no reason given, (b) three persons were ineligible because they had been on dialysis for less than three months, (c) one person did not speak English, and (d) one person was unable to make informed consent due to cognitive impairment. Only one person required data to be collected over two separate dialysis days due to fatigue. All other participants were able to complete the study during one dialysis session. Data collection time typically lasted between 30-60 minutes per person. A total of 73 persons completed the study.

Preliminary Examination of Data

All data were entered into SPSS version 15.0. Five instruments required calculation of scores. These computations were done by creating new variables in SPSS using formulas to determine scale totals. Ferrans' syntax for the Quality of Life Index-Dialysis (QLI-D) was used to score the QLI-D and the four subscales. Cronbach's alpha was determined for each instrument to check for internal reliability. Scores were acceptable (Gliner & Morgan, 2000) and ranged from 0.622–0.937 (see Table 1).

Table 1

Internal Reliability of Instruments

Instrument	Cronbach's alpha
Dialysis Symptom Index	0.867
Hospital Anxiety and Depression Scale- Total	0.779
Hospital Anxiety and Depression Scale- Anxiety subscale	0.805
Hospital Anxiety and Depression Scale- Depression subscale	0.622
Inventory of Functional Status- Dialysis	0.860
Quality of Life Index- Dialysis	0.937

The QLI-D required calculating the Cronbach's alpha without item 22. Item 22 was to be answered by participants who were employed. Because only 12 participants

were employed, resulting in a low response rate for that item, SPSS was unable to run the calculation with item 22 included. Therefore, the Cronbach's alpha was determined without item 22.

To visually check for missing data and extreme values, frequencies were run on all variables. There was one missing data point regarding income level. Because this question was on the back of the demographic form, it was most likely overlooked during data collection. One extreme value was found. A hemoglobin value was recorded as 37.7. The PI questioned whether a hematocrit value had been entered instead of a hemoglobin level. The charge nurse at the dialysis center was contacted by telephone and the correct value, 13.1, was obtained. The errant value was replaced by the correct value in the database. No other extreme values were noted.

The data were also visually examined for outliers and linearity by means of scatterplots which graphed each continuous independent variable against the dependent variable, quality of life. One outlier was noted on the QLI-D. Due to this finding, additional regression analyses were conducted to examine the results without the outlier.

Each continuous variable was tested for normality by examining skewness and kurtosis statistics. Variables were considered normally distributed if skewness and kurtosis values were between -1 and +1. Three variables did not fall within this range: (a) time on hemodialysis, (b) serum albumin, and (c) the Family subscale of the QLI-D. The variable *time on dialysis* was positively skewed and a square root transformation was applied. The variables *serum albumin* and *Family subscale* were negatively skewed. Before a transformation could be applied, the variables were reflected. To reflect each

variable, the highest value in the distribution was determined and increased by one to form a constant that was higher than every value. Each value was then subtracted from this constant yielding reverse scores and a positively skewed distribution. Following reflection, a square root transformation was applied. These transformations significantly improved both skewness and kurtosis (see Table 2). All other continuous variables demonstrated skewness and kurtosis values between the acceptable range of -1 and +1.

Table 2

The Effect of Data Transformation on Skewness and Kurtosis

Variable	Pre-transformation		Post-transformation	
	Skewness	Kurtosis	Skewness	Kurtosis
Time on hemodialysis	1.734	3.615	0.700	-0.117
Serum albumin	-1.300	4.230	0.105	1.125
Family subscale	-1.130	0.571	0.496	-0.731

Characteristics of the Individual and Environment

The sample consisted of 73 hemodialysis patients from one dialysis center. Most of the participants were female (55%), African American (76%) and not married (67%). Over half reported household incomes above the federal poverty level (56%) and felt they were not likely to receive a kidney transplant (58%). Ages ranged from 20 to 89 years old, with a mean age of 56 years ($SD = 15.8$). Time on hemodialysis ranged from 3

months (the study's minimum allowed) to 301 months (25 years) with a mean of 56 months ($SD = 58.3$). Demographic data are displayed in Table 3.

Table 3

Demographic Statistics (N = 73)

Variable	Frequency (%)	
<hr/>		
Gender		
Female	40	(55%)
Male	33	(45%)
Race/ ethnicity		
African American	56	(76%)
White	13	(18%)
Hispanic	2	(3%)
Other	2	(3%)
Marital status		
Married	24	(33%)
Never married	21	(29%)
Divorced/ separated	15	(20%)
Widowed	13	(18%)
Annual family income		
Above poverty	41	(56%)
Below poverty	22	(30%)
Do not know	6	(8%)
Prefer not to answer	3	(4%)
Missing data	1	(2%)
Likelihood of transplant		
Not likely	37	(51%)
Probably not likely	5	(7%)
Somewhat likely	8	(11%)
Very likely	16	(22%)
I do not know	7	(9%)

Health-Related Variables

The health-related variables in the model consisted of biological factors, symptoms, functional status, general health perception, and overall quality of life.

Descriptive results of each variable are summarized in Table 4.

Table 4

Health-Related Variables (N = 73)

Variable	Mean	SD	Range	Possible Range
Serum albumin	3.90 g/dL	0.40	2.1–4.6	3.5–4.5 (normal range)
Serum hemoglobin	12.58 g/dL	1.67	9.4–17.8	12–16 (normal range)
Dialysis symptoms	41.85	23.30	5–110	0–150
Anxiety	6.52	4.27	0–18	0–21
Depression	5.36	3.16	0–15	0–21
Fatigue	43.27	27.36	0–100	0–100
Functional status (IFS)	3.00	0.65	1.47–4.00	1–4
Functional status (PPS)	75.89	13.42	50–100	0–100
General health perception	5.67	1.83	1–10	1–10
Quality of life- overall	21.14	4.87	7.45–30.00	0–30
Health and functioning	18.92	5.48	4.00–30.00	0–30
Socioeconomic	21.57	5.81	5.50–30.00	0–30
Psychological/ spiritual	22.96	5.73	8.50–30.00	0–30
Family	24.71	5.40	8.20–30.00	0–30

Research Question #1

What is the quality of life for persons on hemodialysis?

The overall quality of life was 21.14 ($SD = 4.87$) out of a possible score of 30. A higher score on the QLI-D indicates a higher quality of life, thus the average reported score is higher than the midrange value of 15. Each subscale was also measured on a 0-30 scale. The health and functioning subscale was the lowest rated subscale ($M = 18.92$, $SD = 5.48$), followed by the socioeconomic subscale ($M = 21.57$, $SD = 5.81$), the psychological/ spiritual subscale ($M = 22.96$, $SD = 5.73$), and the family subscale ($M = 24.71$, $SD = 5.40$).

Simple correlations were conducted to inspect the relationships between all continuous variables in the study (see Table 5). Six variables significantly correlated with quality of life: (a) dialysis symptoms, (b) anxiety, (c) depression, (d) fatigue, (e) palliative performance scale, and (f) general health perception. These correlations were low to moderate in strength (Munro, 2005).

Table 5

Intercorrelations of Continuous Variables (N = 73)

Variables	1	2	3	4	5	6	7	8	9	10	11	12
1. QLI-D	–	.099	-.080	-.480 **	-.502 **	-.576 **	-.282 *	.172	.256 *	.583 **	.180	.165
2. Albumin		–	.313 **	-.104	-.259 *	-.294 *	-.049	.343 **	.283 *	.198	-.197	.327 **
3. Hemoglobin			–	.066	-.092	.152	.107	-.283 *	-.303 **	-.097	.043	.141
4. DSI				–	.403 **	.390 **	.394 **	-.067	-.241 *	-.465 **	-.159	.003
5. Anxiety					–	.352 **	.085	-.019	-.076	-.244 *	-.400 **	-.208
6. Depression						–	.325 **	-.350 **	-.281 *	-.394 **	-.001	-.352 **
7. Fatigue							–	-.159	-.258 *	-.280 *	-.023	-.165
8. IFS-D								–	.695 **	.296 *	-.524 **	.213
9. PPS									–	.277 *	-.407 **	.251 *
10. GHP										–	-.024	.135
11. Age											–	-.119
12. Time on dialysis												–

Variables:

QLI-D = Quality of Life Index- Dialysis

DSI = Dialysis Symptom Index

IFS = Inventory of Functional Status- Dialysis

PPS = Palliative Performance Scale

GHP = General Health Perception

* $p \leq .05$ ** $p < .001$

Research Question #2

Do biological function (serum albumin and serum hemoglobin), symptoms (dialysis symptoms, anxiety, depression, and fatigue), functional status, and general health perception explain quality of life in persons with ESRD?

Using multiple regression, the influence of the health-related factors of the revised Wilson and Cleary model (Ferrans et al., 2005) on quality of life was examined. Prior to running the analysis, an independent *t*-test was conducted to test for differences between men and women's hemoglobin levels. If this test was significant, the variable would have been recoded as "normal" or "abnormal" according to gender-specific guidelines. No statistical differences between men and women's hemoglobin values were found ($t = -1.483, p = 0.142$). Therefore, the decision was made to include hemoglobin as a continuous variable in the regression analysis.

Before examining the regression statistics, inspections for assumptions and other potential problems that may affect interpreting the analysis were conducted. Initially, the output was examined for any issues with multicollinearity. Bivariate correlations showed no strong positive or negative correlations (all were correlated less than 0.85). In addition, the tolerance values were all greater than 0.10 and the variance inflation factors were all less than 10.0, revealing no concerns with multicollinearity (Mertler & Vannatta, 2002). Next, the data were checked for multivariate outliers. All standardized residual values fell between -3.0 and 3.0, indicating no issues with outliers (Tabachnick & Fidell, 2001). Finally, the assumptions of multiple regression—multivariate normality, linearity, and homoscedasticity—were checked by examining a scatterplot of predicted values and

residuals. The plot had points equally distributed around the midpoint, with no discernible patterns noted (Polit, 1996). Therefore, all assumptions were sufficiently met.

To answer the research question, all nine independent variables were entered together as one block. This model significantly explained 59% ($R^2 = 0.589$; $R^2_{\text{adj}} = 0.530$) of the variance in overall quality of life, $F = 9.887$ (9, 62), $p < 0.001$. The significant variables contributing to the model were serum albumin (square root), anxiety, depression, and general health perception (see Table 6).

Table 6

Multiple Regression Summary for Health-Related Variables (N = 73)

	Standardized Regression Coefficient	<i>t</i>	<i>p</i>
Albumin (square root)	0.206	2.010	0.049*
Hemoglobin	0.071	0.720	0.474
Dialysis Symptom Index	-0.021	-0.193	0.848
HADS- Anxiety subscale	-0.297	-3.149	0.003*
HADS- Depression subscale	-0.368	-3.584	0.001*
Fatigue VAS	-0.018	-0.194	0.847
Inventory of Functional Status- Dialysis	-0.118	-0.947	0.347
Palliative Performance Scale (PPS)	0.189	1.515	0.135
General Health Perception	0.370	3.719	<0.001*
$R^2 = 0.589$ $R^2_{adj} = 0.530$ $F = 9.887$ $p < 0.001$ * $p < 0.05$			

Research Question #3

Do biological function (serum albumin and serum hemoglobin), symptoms (dialysis symptoms, anxiety, depression, and fatigue), functional status, general health perception, characteristics of the individual (age, gender, race/ ethnicity), and

characteristics of the environment (time on dialysis, marital status, and SES status) explain quality of life in persons with ESRD?

This question includes characteristics of the individual and environment in addition to the health-related variables. Four of the nominal variables in this analysis (gender, race/ ethnicity, marital status, and SES status) required dummy coding prior to entering into the model. These variables were coded as dichotomous variables (Munro, 2005) according to the most frequent response. The dummy codes are listed in Table 7.

Table 7

Dummy Coding for Nominal Variables

	Reference Value = 1	Non-reference values = 0
Gender	Female	Male
Race/ ethnicity	African American	White Hispanic American Indian Other Prefer not to answer
Marital status	Married	Never married Divorced Separated Widowed Prefer not to answer
Socioeconomic status	Above federal poverty level	Below federal poverty level Do not know Prefer not to answer

The regression output was initially examined for assumptions and problems that might affect confidence in the results. Bivariate correlations were less than 0.85, tolerance values were all greater than 0.10, and variance inflation factors were all less than 10. Therefore, no problems were noted with multicollinearity. Standardized residual values indicated no issues with multivariate outliers. The scatterplot of predicted and residual values demonstrated that the assumptions of multiple regression were met.

All of the 15 independent variables were entered together as one block. This model significantly explained 61% ($R^2 = 0.608$; $R^2_{\text{adj}} = 0.501$) of the variance in overall quality of life, $F = 5.693$ (15, 55), $p < 0.001$. The significant variables contributing to the model were anxiety, depression, and general health perception (see Table 8).

Table 8

Multiple Regression Summary for All Variables on Overall Quality of Life (N = 73)

	Standardized Regression Coefficient	<i>t</i>	<i>p</i>
Albumin (square root)	0.151	1.333	0.188
Hemoglobin	0.096	0.890	0.378
Dialysis Symptom Index	0.014	0.119	0.906
HADS- Anxiety subscale	-0.286	-2.439	0.018*
HADS- Depression subscale	-0.413	-3.645	0.001*
Fatigue VAS	-0.020	-0.198	0.844
Inventory of Functional Status- Dialysis	-0.117	-0.797	0.429
Palliative Performance Scale (PPS)	0.230	1.671	0.100
General Health Perception	0.363	3.303	0.002*
Age	0.046	0.361	0.719
Female gender	0.064	0.604	0.549
African American race	0.043	0.455	0.651
Time on hemodialysis (square root)	-0.105	-1.027	0.309
Married status	0.074	0.769	0.445
Income above poverty	-0.002	-0.018	0.986
$R^2 = 0.608$ $R^2_{adj} = 0.501$ $F = 5.693$ $p < 0.001$ * $p < 0.05$			

Research Question #4

Do biological function (serum albumin and serum hemoglobin), symptoms (dialysis symptoms, anxiety, depression, and fatigue), functional status, general health perception, characteristics of the individual (age, gender, race/ ethnicity), and characteristics of the environment (time on dialysis, marital status, and SES status) explain dimensions of quality of life (health and functioning, socioeconomic, psychological/ spiritual, and family) in persons with ESRD?

To examine the total model's influence on each of the quality of life subscales, four separate regression analyses were conducted. Each regression model had a different dependent variable: (a) health and functioning dimension, (b) socioeconomic dimension, (c) psychological/ spiritual dimension, and (d) family dimension. The 15 independent variables were entered together as one block. For all four analyses, the assumptions for multiple regression were met as demonstrated by residual scatterplots. There were no multivariate outliers or problems with homoscedasticity.

Regression #1: Health and functioning dimension. The R^2 of 0.644 ($R^2_{\text{adj}} = 0.547$) indicated that over half of the variability in the health and functioning dimension was explained by the independent variables, $F = 6.628 (15, 55), p < 0.001$. The significant variables contributing to this model were depression and general health perception (see Table 9).

Regression #2: Socioeconomic dimension. This model significantly explained 50% ($R^2 = 0.503, R^2_{\text{adj}} = 0.368$) of the variance in the socioeconomic dimension, $F =$

3.712 (15, 55), $p < 0.001$. The significant variables contributing to the model were anxiety, depression and general health perception (see Table 10).

Regression #3: Psychological/ spiritual dimension. A significant F value of 3.712 (15, 55), $p < 0.001$ indicated that the model explained 52% ($R^2 = 0.520$, $R^2_{\text{adj}} = 0.388$) of the variance in the psychological/ spiritual dimension. The significant contributing variables were again anxiety, depression and general health perception (see Table 11).

Regression #4: Family dimension. This model significantly explained 39% ($R^2 = 0.385$, $R^2_{\text{adj}} = 0.211$) of the variance in the psychological/ spiritual dimension, $F = 2.210$ (15, 53), $p = 0.018$. The only significant variable contributing to the model was anxiety (see Table 12).

Table 9

Multiple Regression Summary for All Variables on Health and Functioning (N = 73)

	Standardized Regression Coefficient	<i>t</i>	<i>p</i>
Albumin (square root)	0.059	0.545	0.588
Hemoglobin	0.057	0.560	0.578
Dialysis Symptom Index	0.044	0.380	0.705
HADS- Anxiety subscale	-0.201	-1.793	0.078
HADS- Depression subscale	-0.480	-4.444	<0.001*
Fatigue VAS	-0.128	-1.350	0.182
Inventory of Functional Status- Dialysis	-0.069	-0.493	0.624
Palliative Performance Scale (PPS)	0.192	1.460	0.150
General Health Perception	0.334	3.195	0.002*
Age	0.022	0.181	0.857
Female gender	0.045	0.440	0.662
African American race	0.104	1.152	0.254
Time on hemodialysis (square root)	-0.087	-0.888	0.379
Married status	-0.008	-0.089	0.930
Income above poverty	-0.055	-0.543	0.589
$R^2 = 0.644$ $R^2_{adj} = 0.547$ $F = 6.628$ $p < 0.001$ * $p < 0.05$			

Table 10

Multiple Regression Summary for All Variables on Socioeconomic Dimension (N = 73)

	Standardized Regression Coefficient	<i>t</i>	<i>p</i>
Albumin (square root)	0.099	0.776	0.441
Hemoglobin	0.033	0.274	0.785
Dialysis Symptom Index	0.061	0.449	0.655
HADS- Anxiety subscale	-0.305	-2.307	0.025*
HADS- Depression subscale	-0.296	-2.321	0.024*
Fatigue VAS	0.012	0.104	0.918
Inventory of Functional Status- Dialysis	-0.164	-0.996	0.324
Palliative Performance Scale (PPS)	0.250	1.614	0.112
General Health Perception	0.282	2.284	0.026*
Age	0.107	0.750	0.457
Female gender	0.176	1.475	0.146
African American race	-0.069	-0.646	0.521
Time on hemodialysis (square root)	-0.177	-1.530	0.132
Married status	0.149	1.372	0.176
Income above poverty	0.160	1.329	0.189
$R^2 = 0.503$ $R^2_{adj} = 0.368$ $F = 3.712$ $p < 0.001$ * $p < 0.05$			

Table 11

*Multiple Regression Summary for All Variables on Psychological/ Spiritual Dimension
(N = 73)*

	Standardized Regression Coefficient	<i>t</i>	<i>p</i>
Albumin (square root)	0.157	1.251	0.216
Hemoglobin	0.171	1.437	0.156
Dialysis Symptom Index	0.000	-0.001	1.000
HADS- Anxiety subscale	-0.272	-2.089	0.041*
HADS- Depression subscale	-0.348	-2.772	0.008*
Fatigue VAS	0.082	0.745	0.459
Inventory of Functional Status- Dialysis	-0.077	-0.473	0.638
Palliative Performance Scale (PPS)	0.188	1.236	0.222
General Health Perception	0.352	2.898	0.005*
Age	0.102	0.729	0.469
Female gender	-0.122	-1.033	0.306
African American race	0.071	0.678	0.501
Time on hemodialysis (square root)	-0.051	-0.451	0.654
Married status	0.037	0.342	0.733
Income above poverty	-0.092	-0.780	0.439
$R^2 = 0.520$ $R^2_{adj} = 0.388$ $F = 3.964$ $p < 0.001$ * $p < 0.05$			

Table 12

Multiple Regression Summary for All Variables on Family Dimension (N = 73)

	Standardized Regression Coefficient	<i>t</i>	<i>P</i>
Albumin (square root)	-0.251	-1.709	0.093
Hemoglobin	-0.057	-0.678	0.501
Dialysis Symptom Index	0.126	0.819	0.417
HADS- Anxiety subscale	0.355	2.327	0.024*
HADS- Depression subscale	0.156	1.081	0.285
Fatigue VAS	-0.186	-1.510	0.137
Inventory of Functional Status- Dialysis	0.183	0.982	0.331
Palliative Performance Scale (PPS)	-0.140	-0.802	0.426
General Health Perception	-0.175	-1.258	0.214
Age	0.068	0.419	0.677
Female gender	-0.166	-1.237	0.222
African American race	-0.012	-0.096	0.924
Time on hemodialysis (square root)	0.144	1.073	0.288
Married status	-0.191	-1.561	0.125
Income above poverty	0.034	0.251	0.803
$R^2 = 0.385$ $R^2_{\text{adj}} = 0.211$ $F = 2.210$ $P = 0.018$ * $p < 0.05$			

Research Question #5

When controlling for characteristics of the individual (age, gender, and race) and characteristics of the environment (marital status, socioeconomic status, and time on hemodialysis), do biological function (serum albumin and serum hemoglobin), symptoms (dialysis symptoms, anxiety, depression, and fatigue), functional status, and general health perception explain quality of life in persons with ESRD?

Sequential regression was employed to determine if the addition of health-related variables to the model improved the explanation of variance in overall quality of life after the characteristics of the individual and the environment were already taken into account. Characteristics of the individual and characteristics of the environment were entered into the multiple regression model as the first block, and the other health-related variables were entered together as the second block. The assumptions for multiple regression were met as demonstrated by residual scatterplots. There were no multivariate outliers or problems with homoscedasticity.

Characteristics of the individual and environment did not significantly contribute to overall quality of life, $F = 1.310$ (6, 64), $p = 0.266$. However, after controlling for individual and environmental characteristics, model two significantly explained 61% ($R^2 = 0.608$, $R^2_{\text{adj}} = 0.501$) of the variance in overall quality of life, $F = 7.781$ (9, 55), $p < 0.001$. Again, anxiety, depression, and general health perception were the only significant contributing variables (see Table 13).

Table 14 provides a comparison of all the regression models and the resulting significant variables. Post-hoc power analyses indicated that all models had 99% power to detect differences if such differences existed.

Table 13

*Multiple Regression Summary Controlling for the Individual and the Environment
(N = 73)*

Model		Standardized Regression Coefficient	<i>t</i>	<i>p</i>
1	Age	0.202	1.561	0.123
	Female gender	-0.093	-0.678	0.501
	African American race	0.176	1.399	0.167
	Married status	0.144	1.139	0.259
	Income above poverty	0.086	0.624	0.535
	Time on hemodialysis (square root)	0.110	0.905	0.369
2	Age	0.046	0.361	0.719
	Female gender	0.064	0.604	0.549
	African American race	0.043	0.455	0.651
	Married status	0.074	0.769	0.445
	Income above poverty	-0.002	-0.018	0.986
	Time on hemodialysis (square root)	-0.105	-1.027	0.309
	Albumin (square root)	0.151	1.333	0.188
	Hemoglobin	0.096	0.890	0.378
	Dialysis Symptom Index	0.014	0.119	0.906
	HADS- Anxiety subscale	-0.286	-2.439	0.018*
	HADS- Depression subscale	-0.413	-3.645	0.001*
	Fatigue VAS	-0.020	-0.198	0.844
	Inventory of Functional Status- Dialysis	-0.117	-0.797	0.429
	Palliative Performance Scale (PPS)	0.230	1.671	0.100
	General Health Perception	0.363	3.303	0.002*
1	R ² = 0.109			
	R ² _{adj} = 0.026			
	F = 1.310			
	p = 0.266			
2	R ² = 0.608			
	R ² _{adj} = 0.501			
	F = 7.781			
	p < 0.001			
* denotes significance				

Table 14

A Comparison of All Multiple Regression Models (N = 73)

Model*	1	2	3	4	5	6	7
R^2	0.589	0.608	0.644	0.503	0.520	0.385	0.109 0.608
R^2_{adj}	0.530	0.501	0.547	0.368	0.388	0.211	0.026 0.501
F	9.887	5.693	6.628	3.712	3.964	2.210	1.310 5.693
p	<0.001	<0.001	<0.001	<0.001	<0.001	0.018	0.266 <0.001
Significant variables							
Anxiety	✓	✓		✓	✓	✓	✓
Depression	✓	✓	✓	✓	✓		✓
General Health Perception	✓	✓	✓	✓	✓		✓
Albumin	✓						

*Model Descriptions:

1 = All health-related variables on overall quality of life

2 = All variables on overall quality of life

3 = All variables on health and functioning subscale

4 = All variables on socioeconomic subscale

5 = All variables on psychological/ spiritual subscale

6 = All variables on family subscale

7 = Controlling for characteristics of the individual and environment in block one

Additional Analyses

After examination of the results, additional analyses were conducted based on the findings. The first analysis was done to remove the one outlier case of the QLI-D and all the regression models were recalculated. The second analysis examined the impact of only significant bivariate correlates of the QLI-D on quality of life. The third analysis explored the influence of all the nonsignificant independent variables in the initial regression models on quality of life. Finally, a regression analysis was conducted to more clearly examine anxiety and depression as concepts separate from other dialysis symptoms.

Additional analysis #1: Regressions repeated without outlier (N = 72). When examining scatterplots of the various independent variables and the QLI-D, one case consistently appeared as an outlier due to the low value of the QLI-D. This participant scored 7.45 on the QLI-D whereas the mean QLI-D was 21.14 ($SD = 4.87$). The next highest QLI-D score was 11.74. The standardized score for the potential outlier was -2.81. Although still within three standard deviations of the mean, this participant was clearly a borderline case.

Because regression equations can be sensitive to outliers, the regression models were reexamined excluding the borderline case. All regression models were rerun using the exact methods described earlier. Exclusion of this one case resulted in similar results (see Table 15).

Table 15

Comparison of Regression Results With ($N = 73$) and Without ($N = 72$) a Borderline Case

Model	R^2	R^2_{adj}	F	p
1				
With	0.589	0.530	9.887	< 0.001
Without	0.604	0.546	10.350	< 0.001
2				
With	0.608	0.501	5.693	< 0.001
Without	0.625	0.521	5.999	< 0.001
3				
With	0.644	0.547	6.628	< 0.001
Without	0.646	0.547	6.562	< 0.001
4				
With	0.503	0.368	3.712	< 0.001
Without	0.510	0.374	3.743	< 0.001
5				
With	0.520	0.388	3.964	< 0.001
Without	0.538	0.409	4.186	< 0.001
6				
With	0.385	0.211	2.210	0.018
Without	0.384	0.206	2.158	0.021
7				
With				
Block 1	0.109	0.026	1.310	0.266
Block 2	0.608	0.501	5.693	< 0.001
Without				
Block 1	0.126	0.043	1.518	0.187
Block 2	0.625	0.521	5.999	< 0.001

In the majority of the regressions conducted, the R^2 and R^2_{adj} increased slightly for each model after omitting the borderline case. The significant contributing variables for each model were identical, except for model one which regressed all health-related variables on quality of life. With the borderline case included in the model, the significant contributing variables were: anxiety, depression, general health perception, and albumin. Without the borderline case, albumin ceased to be a significant variable ($p = 0.055$).

Additional analysis #2: Significant bivariate correlates on quality of life. The statistical analysis conducted for research question #3 included 15 independent variables regressed on overall quality of life. Having a large number of independent variables tends to overestimate the R^2 (Tabachnick & Fidell, 2001). Therefore the R^2 is adjusted to take into account both the number of independent variables and the sample size. To explore how the independent variables may contribute to quality of life, an additional regression analysis was conducted using only variables that were significantly correlated with quality of life (see Table 5). These variables included: (a) dialysis symptoms, (b) anxiety, (c) depression, (d) fatigue, (e) function as measured by the Palliative Performance Scale, and (f) general health perception. The R^2 was higher for the original model (0.608) when compared to the exploratory model (0.574), indicating that the other variables contributed to quality of life. However, the subsequent analysis did slightly improve the R^2_{adj} from 0.501 to 0.534. The variables contributing significantly to the model remained the same for both the original and exploratory analyses: (a) anxiety, (b) depression, and (c) general health perception.

Additional analysis #3: Insignificant variables on quality of life. Three independent variables consistently and significantly contributed to quality of life. To determine if the other variables were being obscured by these three variables, a regression analysis was conducted omitting the three significant variables. Although the overall model was significant ($p = 0.004$), the R^2 (0.369) and the R^2_{adj} (0.239) were greatly reduced. Only two variables significantly contributed to the model, dialysis symptoms ($p = 0.001$) and age ($p = 0.036$).

Additional analysis #4: Anxiety and depression separate from other symptoms. To answer the research questions, both the Dialysis Symptom Index (DSI) and the Hospital Anxiety and Depression Scale (HADS) were used to measure symptoms. Anxiety and/ or depression, as measured by the HADS, significantly contributed to every regression model. The DSI also includes four questions representing anxiety and depression. The DSI was modified by summing the scores after removing the following symptoms: (a) item 22: worrying, (b) item 23: feeling nervous, (c) item 27: feeling sad, and (d) item 28: feeling anxious. A regression analysis was conducted with all 15 independent variables entered as one block using the modified DSI. The result of this regression analysis ($R^2 = 0.612$, $R^2_{\text{adj}} = 0.506$) was almost identical to the original results ($R^2 = 0.608$, $R^2_{\text{adj}} = 0.501$). The same three variables (anxiety, depression, and general health perception) significantly contributed to both models. Although the modified DSI was not a significant factor, the p value of this variable in the model went from 0.906 in the original analysis to 0.490 in this analysis.

Summary

Seventy-three persons on hemodialysis were interviewed to determine overall quality of life, as well as factors affecting quality of life. The participants were mostly African American females living above the poverty level, with a mean age of 56 and a mean time on hemodialysis of over four years. The overall quality of life was 21.14, with the health and functioning dimension of quality of life having the lowest score and the family-related dimension of quality of life having the highest. Several multiple regression models were used to examine which factors best explained overall quality of life. When all variables were included in the model, they explained 61% of the overall quality of life. Characteristics of the individual and characteristics of the environment did not contribute significantly to any of the models. Health-related variables significantly contributing to quality of life included anxiety, depression, general health perception, and albumin.

CHAPTER V

DISCUSSION

The purpose of this study was to describe the quality of life in persons with end stage renal disease (ESRD) and examine factors which influence quality of life. This chapter provides an interpretation of the findings as well as implications for nursing practice. Recommendations for future research are suggested.

Interpretation of Results

Quality of life. The mean quality of life for this sample was 21.14 ($SD = 4.87$). This finding was similar to other studies that have administered the Quality of Life Index-Dialysis (QLI-D) to persons with ESRD (Bihl et al., 1988; Ferrans & Powers, 1993; Greene, 2005; Jablonski, 2007; Laws et al., 2000). These studies reported mean quality of life scores between 20.70 – 22.67. Reported mean quality of life scores using the QLI for other populations include: (a) 17.4 ($SD = 5.4$) for persons living with chronic pain (Gerstle, All, & Wallace, 2001) (b) 19.4 ($SD = 4.8$) for persons with chronic lung disease (Verrill, Barton, Beasley, & Lippard, 2005), (c) 20.2 ($SD = 4.6$) for residents of nursing homes (Franks, 2004), (d) 21.0 (no SD reported) for persons with heart failure (Scott, Setter-Kline, & Britton, 2004), (e) 21.01 ($SD = 4.27$) for persons with spinal cord injuries (May & Warren, 2002), and (f) 22.74 ($SD = 4.64$) for women following coronary artery bypass graft (Penckofer, Ferrans, Fink, Barrett, & Holm, 2005). The persons with ESRD in this study reported a quality of life better than all these populations, except for women

following heart surgery. In fact, the mean was only slightly lower than a group of healthy persons ($M = 21.9$) using the general population version of the QLI (Ferrans, Cohen, & Smith, 1992). These findings are contrary to a published study which reported a lower quality of life for persons with ESRD compared to persons with other chronic illnesses (Loos et al., 2003). However, the researchers used the SF-36 to measure quality of life which may have measured health status rather than quality of life.

The study findings suggest that persons with ESRD experience a relatively comparable quality of life. Given their symptom burden and intensive dialysis regimen, such findings may seem curious. However, it has been suggested that people adjust their life aspirations according to changes in life circumstances to maintain subjective well-being (Ferrans & Powers, 1993). The results of this study indirectly support such an adaptation. The comparatively normal quality of life demonstrated in this study is a particularly encouraging finding because it suggests that the complex medical care required for this population provides a manageable quality of life. In addition, it lends support to the large amounts of federal funding dedicated to the care of persons with ESRD.

The health and functioning subscale of the QLI-D was the lowest rated subscale ($M = 18.92$, $SD = 5.48$). It was over 2 points lower than the overall quality of life score. The family subscale was the highest of all the scales ($M = 24.71$, $SD = 5.40$). These findings are similar to Ferrans and Powers' (1993) study of 349 persons undergoing hemodialysis in Illinois in which the health and functioning subscale was the lowest subscale score ($M = 18.64$, $SD = 5.71$) and the family subscale was the highest ($M =$

25.25, $SD = 5.07$). These findings support the heavy disease burden felt by persons with ESRD. The large impact that health and functioning have on overall quality of life is the reason why many medical studies examining quality of life focus exclusively on disease burden. Thus, the concept *health-related quality of life* might likely be measured by the health and functioning subscale of the QLI-D.

The fact that the health and functioning subscale was the only subscale mean that was lower than the overall quality of life mean suggests that persons struggling with poor health and functioning may place greater importance on non-health factors to rebalance their quality of life. According to Ferrans' model (1996), socioeconomic, psychological/spiritual, and family domains also contribute to overall quality of life. The socioeconomic subscale was the next lowest subscale score in this study. Almost a third of respondents reported that their annual household income was below the federal poverty level. Given that socioeconomic factors are more difficult to change, especially when on a fixed income due to disability, the two remaining domains may be pivotal in contributing to overall quality of life. Both the psychological/spiritual and family subscales were rated high in this study. These two domains may provide needed resources to cope with what would otherwise be a poorer quality of life. Family and faith are more controllable factors than health and money. Leaning on family and deepening one's faith may be strategies employed by persons with ESRD to improve their overall quality of life.

Health-related factors. The nine health-related factors in the model significantly explained 59% of the variance in overall quality of life. This finding lends support to the

important role that health-related factors play in quality of life. However, only albumin, anxiety, depression, and general health perception were significant variables.

Biological function. Albumin and hemoglobin were the two biological factors selected for this study. Albumin significantly contributed to quality of life when the independent variables were limited to health-related factors. However, the significance level for albumin was borderline ($p = 0.049$) and when an outlier case was removed from the model, it ceased to be significant ($p = 0.055$). Albumin was also not significant when the non-health-related variables were added to the model. When examining bivariate correlations, albumin did not significantly correlate with overall quality of life ($r = 0.099$). These findings are similar to an earlier study that did not find a significant correlation between albumin and quality of life (Patel et al., 2002). Studies that did find a significant relationship between albumin and quality of life (Lopes et al., 2007; Morsch et al., 2006) used a health status instrument, implying that albumin may impact health more than quality of life. This may explain why albumin was only significant when the health-related factors were examined. One study using the QLI-D did find a significant relationship between albumin and overall quality of life, but only in severely malnourished persons (Laws et al., 2000). Severely malnourished was defined using numerous objective and subjective assessment data, not just albumin levels. In the present study, only 10% of the sample had a suboptimal albumin level and, more than likely, less than 10% would be classified as severely malnourished. Thus, albumin may not impact quality of life unless it reaches a critically low level. The present study did not have enough critically low albumin levels to detect this relationship. In fact, the

variable was negatively skewed requiring reflection and transformation before multivariate analyses.

Hemoglobin also did not contribute to any of the regression models and did not significantly correlate with quality of life. Other studies report similar results (Frank et al., 2003; Kalantar-Zadeh et al., 2001; Patel et al., 2002). The studies which did find a significant correlation between hemoglobin and quality of life all used the SF-36 to measure quality of life and not a holistic quality of life scale (Baiardi et al., 2002; Lopes et al., 2007; Morsch et al., 2006). Therefore, like albumin, hemoglobin may be a better determinant of health status than quality of life. Although 43% of participants in this study had hemoglobin levels less than normal, the reason it did not significantly contribute to quality of life may be that their bodies have adapted to persistently low levels and thus, they do not experience symptoms that other persons with low hemoglobin levels might report. In fact, in the present study, hemoglobin did not significantly correlate with fatigue ($r = 0.107$, $p = 0.368$), a common symptom of anemia. In addition, supplemental erythropoietin injections often assist dialysis patients in maintaining adequate hemoglobin levels. Thus, persons on hemodialysis may be able to sustain normal hemoglobin levels or adapt to low levels, rendering it an insignificant factor in perceived quality of life. As measures of biological function, the results of this study did not provide convincing support that either albumin or hemoglobin contributes to overall quality of life in persons with ESRD.

Symptoms. Dialysis symptoms, fatigue, anxiety, and depression were the symptom factors selected for this study. Dialysis symptoms, as measured by the Dialysis

Symptom Index (DSI), were prevalent. The DSI is comprised of 30 symptoms common to persons on dialysis. Participants in this study reported from 2 – 29 symptoms, with a mean of 12.95 ($SD = 5.93$) symptoms. This total number of symptoms is more than other studies which have reported 5.67 (Jablonski, 2007), 7.7 (Frank et al., 2003), and 9.8 (Weisbord et al., 2005) total symptoms. Because Weisbord used the DSI, only his results are truly comparable to this study. The mean total DSI score for this study, which takes into account the severity of symptoms, was 41.85 ($SD = 23.30$). The median value was 38. Although Weisbord (2005) did not report a mean, the median was 25. Therefore, the participants in this study reported a greater number and higher severity of symptoms than have been previously reported. Although the DSI correlated significantly with overall quality of life ($r = 0.480, p < 0.001$), it did not contribute significantly to overall quality of life in the total model. Even when the anxiety and depression items were removed from the scale, the revised DSI still did not explain overall quality of life. These results are intriguing given the heavy symptom burden reported by participants. Jablonski (2007) found that symptom scores, level of relief, and satisfaction with relief accounted for 28% of the variance in quality of life for persons with ESRD. Since her model focused solely on symptoms, it may be that once a more complex model is created, symptoms no longer factor in as a significant determinant of overall quality of life.

Fatigue was also prevalent in this study with over 91% of participants reporting some level of fatigue. Other studies have reported fatigue prevalence between 77% and 90% (Curtin, Bultman, et al., 2002; Frank et al., 2003; Jablonski, 2007; Merkus et al., 1999; Weisbord et al., 2003). Participants in this study reported a mean fatigue level of

43.27 ($SD = 27.36$) using a 100 mm visual analog scale (VAS). This result is similar to another study with African American women on dialysis using a fatigue VAS in which the reported mean was 44.6 ($SD = 33.1$) (Williams et al., 2007). Fatigue exhibited a low, negative correlation with quality of life ($r = -0.282, p = 0.016$), but did not contribute to the overall model. Therefore, fatigue, as well as other common dialysis symptoms, does not seem to be a significant determinant of quality of life in a multi-factorial model. It may be that persons with ESRD are able to adapt to their chronic symptom burden without it interfering significantly with their day-to-day quality of life. Indeed, many of the symptoms are not acute in nature, but might be described by persons on dialysis as dull and nagging. In addition, many symptoms might be adequately managed with medication or other interventions rendering them less of a factor in overall quality of life.

Anxiety was also prevalent in the study sample. Using a cut point of 8 on the anxiety subscale of the Hospital Anxiety and Depression Scale (HADS), 41% of participants were anxious. This finding is much higher than a general population sample which reported anxiety prevalence at 13% (Cohen, Magai, Yaffee, & Walcott-Brown, 2006) and slightly higher than other studies which have reported anxiety among persons with ESRD at 36% (Williams et al., 2007) and 38% (Murtagh et al., 2007). The mean of 6.52 ($SD = 4.27$) was somewhat lower than a study using the HADS with African American women on dialysis that reported a mean of 7.0 ($SD = 3.26$) (Williams et al., 2007). This difference in anxiety levels may be gender-related. In the present study, men had a significantly lower anxiety level than women ($t = 2.340, p = 0.022$). In a study of multiracial older adults, Cohen et al. (2006) also found the prevalence of anxiety to be

higher in women than men. These gender differences may be due to higher reporting of anxiety symptoms by women, greater perceived stress, or other undetermined factors.

Unlike other symptoms examined in the study, anxiety was an important health-related variable. It correlated negatively with quality of life ($r = -0.502, p < 0.001$) and significantly contributed to every regression model, except one which included the health and functioning subscale of the QLI-D as the dependent variable. The reason anxiety did not help explain health and functioning ($p = 0.078$) is unclear. Interestingly, none of the ESRD quality of life studies reviewed included anxiety as an independent variable. Therefore, this finding may provide important insight into a vital determinant of quality of life for persons with ESRD. The reason for its relative absence from the literature may be multi-factorial. Given its prevalent nature, potential nonspecific symptoms, and the possible stigma associated with a psychological disorder, symptoms associated with anxiety might not be assessed by health care providers or reported by persons on dialysis. Therefore, practitioners might not adequately diagnose and treat anxiety. Thus, the true prevalence of anxiety may be underestimated and not considered in quality of life studies.

Depression was another important health-related variable in this study. Using a cut-point of 8 on the HADS, 27% of participants were depressed. This finding mirrored other studies which reported a 28% prevalence rate (Drayer et al., 2006; Murtagh et al., 2007; Weisbord et al., 2005). The mean of 5.36 ($SD = 3.16$) was identical to another study using the HADS in persons with ESRD in which the mean was 5.4 ($SD = 3.52$) (Williams et al., 2007). Like anxiety, depression exhibited a negative correlation with quality of life ($r = -0.576, p < 0.001$) and significantly contributed to every regression

model, except one in which the family subscale of the QLI-D was the dependent variable. Other studies have also reported that depression is associated with a decreased quality of life (Drayer et al., 2006; Sesso et al., 2003; Walters et al., 2002). Although not as prevalent as anxiety, depression appears to be a key determinant for overall quality of life.

Functional status. Function was measured with two instruments, the Inventory of Functional Status- Dialysis (IFS-D) and the Palliative Performance Scale (PPS). The IFS-D is scored by averaging the responses to each instrument item yielding a 1-4 scale total, with a higher number indicating higher functioning. The participants in this study had a mean IFS-D score of 3.00 ($SD = 0.65$). This finding is quite different from a study by the instrument's developer in which the mean IFS-D for 104 dialysis patients was reported to be between 1.29 and 1.37 (Thomas-Hawkins, 2000). This difference may not be due to various populations included in the studies, but rather to validity issues with the tool. The IFS-D lists 17 activities to which respondents self-report how independently they perform each activity (see Appendix E). A key qualifier is that participants must report which activities they *did* do, not which activities they *could* do. This creates issues with some of the items that may be gender-biased. For example, item number eight is "prepared meals." Some persons, especially older men, may never prepare meals because this activity is their spouse's responsibility. Functional capacity, or lack thereof, is not the issue. Given this concern, the author of the IFS-D was contacted before data collection began and permission was granted to modify the instrument to include a "not applicable" response. These questions were deleted from scale calculations, instead of

recording a response of 1 = did not do. Since the scale total is the mean of all items, this modification resulted in higher scale totals. In addition to gender-bias, other biases were noted. For example, item number 13 is “attended church services.” If the participant had never previously participated in faith-based activities, should the item be scored 1 = did not do, or marked as “not applicable” and deleted from calculations? For this study, the later method was employed. Without a “not applicable” alternative, the tool has serious validity issues and reported results using the original scoring should be interpreted with caution. For example, the mean score reported above in the study by Thomas-Hawkins was 1.29 – 1.37. This indicates the average response was somewhere between “did not do” and “did with a lot of help.” This is not a logical ordinal progression and renders the results uninterpretable. Even with the scale modification, the IFS-D did not yield significant results. It did not correlate with overall quality of life nor contribute significantly to any of the regression models.

Function was also measured with the PPS, a scale in which 100 = no evidence of disease and 0 = deceased. The PPS has not been used with the renal population, however, the predecessor to this tool, the Karnofsky Performance Scale (KPS), has. The improvements made to the KPS which resulted in the PPS include more specific descriptions of the five categories for classifying functional decline, as well as the deletion of requirements for hospitalization, as patients often have other non-hospital options at the end-of-life. For this study, the mean PPS score was 75.89 ($SD = 13.42$). In comparison to this study, KPS scores have shown similar results. One study reported a mean KPS of 74.5 ($SD = 16.6$) (Patel et al., 2002), and another reported mean values

between 63.80 – 80.70 (Laws et al., 2000). These similarities lend support to the use of the PPS in the renal population. For this study, the PPS showed a low, positive correlation with overall quality of life ($r = 0.256, p = 0.028$). However, it was not a significant contributor to any of the regression models, including the analysis with the health and functioning subscale as the dependent variable. This finding once again may be a result of adaptation by persons with ESRD to their chronic condition, and the relative value of functional status to overall quality of life.

General health perception. General health perception was measured with a single global question which measured perception of health on a scale from 1 = poor health, to 10 = excellent health. The mean score was 5.67 ($SD = 1.83$). General health perception correlated higher with overall quality of life ($r = 0.583, p < 0.001$) than any of the other independent variables. It was a significant contributor to all the regression models, except one in which the dependent variable was the family subscale of the QLI-D. These results are similar to another study which also measured general health perception with a single 10-point Likert-type scale in two different dialysis populations (Bihl et al., 1988). The mean general health perception for persons on peritoneal dialysis was 5.5 ($SD = 1.99$) and for persons on hemodialysis was 6.5 ($SD = 1.94$). Correlations with quality of life (as measured by the QLI-D) were high for the peritoneal dialysis group ($r = 0.71, p < 0.001$) and moderate for the hemodialysis group ($r = 0.56, p < 0.02$). The significant results of general health perception in the present study, along with the findings reported by Bihl et al., suggest a meaningful relationship between general health perception and quality of life for persons with ESRD.

The significance of general health perception is an important finding. When trying to evaluate quality of life, results from the current study indicate that it may be more important to understand the burden of disease from the person's point of view rather than the practitioner's. During data collection, this researcher found it interesting that some persons with considerable debilitation perceived their health status as good to excellent, while some younger persons on dialysis who appeared more vigorous reported their health status as poor. It may be that when evaluating one's own health status, comparisons are made to persons of a similar age. Older persons on dialysis may perceive that their non-dialysis contemporaries also experience multiple health problems, while younger persons observe few health-related issues in non-dialysis persons their own age. Younger persons on dialysis may grieve their loss of health more intensely than older persons and may not have had enough time to normalize their dialysis lifestyle. Because ESRD is a chronic condition, many persons living with the disease may readjust their definition of health. This "response shift" has been noted in persons as a way to cope with the effects of illness (Ferrans, 2005). The medical regimen associated with renal failure, including diet, medications, and dialysis, may become the new health baseline. Therefore, as long as no other illness processes are occurring, health is maintained according to the person's adjusted internal standards.

Characteristics of the individual. Three characteristics of the individual were selected for inclusion in the study: (a) age, (b) gender, and (c) race/ ethnicity. None of these variables were significant in any of the regression models. According to the United States Renal Data System (2006), the mean age of all persons with ESRD in the United

States is 57.9 years, over half of the persons with ESRD are male (56%), 61% are White, and only 32% are African American. Thus, the participants in this study were slightly younger and consisted of both more females and significantly more African Americans than the U.S. ESRD population.

Age. Age was the only continuous variable in this category and ranged widely from 20 to 89 years, with a mean age of 56 years ($SD = 15.8$). It was not a significant variable, which is similar to the results of a Brazilian study which examined age and quality of life in hemodialysis patients (Morsch et al., 2006). However, other ESRD studies have found that increasing age is associated with a decreased quality of life (Baiardi et al., 2002; Ferrans & Powers, 1993; Frank et al., 2003; Lopes et al., 2007; Walters et al., 2002). All these studies used the SF-36 or the kidney version of the SF-36 to measure quality of life. Therefore, the findings of these earlier studies may be best understood in terms of the relationship between increasing age and health status. This relationship may also be illustrated in the present study. Age significantly correlated with the two functional measures, which may be defined as a measure of health status: (a) Inventory of Functional Status ($r = -0.524, p < 0.001$), and (b) Palliative Performance Scale ($r = -0.407, p < 0.001$). These correlations may better corroborate the earlier findings using the SF-36.

Greene (2005) found that younger dialysis patients had a significantly lower quality of life than older groups of patients. In addition, Ferrans and Powers (1993) also found age to be positively correlated with quality of life. However, for every 20-year increase in age, the QLI-D score only increased by one point. Although age was

statistically significant, it did not seem to be a substantive variable. For this study, age also had a positive although insignificant correlation with quality of life ($r = 0.180$, $p = 0.127$) and was not a significant variable in any of the regression models. Therefore, the results from this study indicate that age is not an important variable in understanding quality of life in persons with ESRD. The reason for these findings may be that the debilitating effects of ESRD are experienced by all ages.

Gender. Both genders were well represented in the study, with 55% of the participants in the study being female. Like age, gender was not a significant variable in any of the regression models. This finding is most comparable to Ferrans and Powers' (1993) study which used the QLI-D with persons on hemodialysis. A regression analysis using backward elimination found gender to be an insignificant variable. Other studies using gender as an independent variable employed health status instruments to measure quality of life (Baiardi et al., 2002; Frank et al., 2003; Kalantar-Zadeh et al., 2001; Lopes et al., 2007; Walters et al., 2002), and therefore, the findings do not compare with the current study. Consequently, gender does not appear to be a characteristic of the individual that impacts overall quality of life for persons with ESRD. This result may be due to similarities between the genders for persons on dialysis. In the present study, most did not work (84%), over half were not married (67%), and their health burdens with regards to ESRD were similar. Thus, men and women on dialysis may not experience gender-specific distinctions which might impact quality of life differently.

Race/ethnicity. The majority of participants in the study were African American (76%), which is somewhat higher than national proportions for ESRD in which African

Americans make up 61% of persons with kidney failure (USRDS, 2006). However, age and gender adjusted rates for African Americans are over four times the rate for Whites (USRDS, 2006). Like the other characteristics of the individual, race was not a significant variable in this study. This finding corroborates Ferrans and Powers' (1993) study which also found no racial differences in quality of life. Their study had a reversed proportional sample in which only 33% of participants were African American and 61% were White. Because Ferrans and Powers' study took place in Illinois, whereas this study took place in North Carolina, the racial difference was most likely due to regional variations of the U.S. population. Other studies which have examined the influence of gender on quality of life used health status instruments to measure quality of life making the results difficult to compare to the present study. This study, along with Ferrans and Powers' study, suggest that race/ ethnicity is not a factor in determining overall quality of life in persons with ESRD. This finding is encouraging given the disproportional burden of ESRD in African Americans.

Characteristics of the environment. Three characteristics of the environment were selected for inclusion in the study: (a) marital status, (b) socioeconomic status, and (c) time on dialysis. Like characteristics of the individual, none of these variables were significant in any of the regression models.

Marital status. The majority of participants in the study were not married (67%). The finding that marital status was not a significant variable was an interesting outcome of this study. However, it supported the work of Ferrans and Powers (1993) who also found no significant relationship between marital status and quality of life. Interestingly,

a large percentage of the participants in this study had never been married (29%). It may be that persons on hemodialysis receive support from other family members and friends, and that marriage is not necessary to receive the emotional and practical benefits that such a committed relationship may impart. The family subscale of the QLI-D was the highest scoring subscale in this study, indicating that participants rated family relationships of high importance and were most satisfied with these relationships.

Socioeconomic status. Only 16% of participants in this study were employed, although 71% were less than 65 years old. Many persons with ESRD do not work due to the weekly time commitment needed for dialysis which often is scheduled during regular work hours and because most also qualify for disability. In the present study, almost one in three participants reported annual household incomes below federal poverty levels. Clearly, financial issues are associated with ESRD disability. However, poverty level was not a significant variable in this study. One reason for this finding may be that most persons on dialysis receive federally sponsored healthcare through the Medicare program. Thus, the participants in this study may not have been financially burdened by their healthcare. Since many health-related variables were examined in this study, Medicare coverage may have mitigated some of the differences that might have been seen with quality of life. In fact, over 87% of participants in this study reported that they were satisfied with their health care (item number two on the QLI-D). Given that most participants had adequate healthcare coverage and were satisfied with it, poverty may not have been a factor in understanding health-related quality of life. The fact that poverty level was not a significant variable in this study supports the findings of Ferrans and

Powers (1993) who found that annual income was not a significant variable in explaining overall quality of life. It may be that persons who experience chronic health issues place less importance on material assets to maintain a sense of well-being.

Time on dialysis. The average time on dialysis for participants in this study was 4.6 years. For these participants, hemodialysis is a permanent way of life as most (58%) felt they were not likely to receive a kidney transplant. Persons on dialysis are immersed in a highly technical, medicalized environment for over 12 hours per week that may serve as a constant reminder of infirmity. However, in the present study, time on dialysis did not contribute significantly to overall quality of life. Two other studies using the QLI-D found similar results (Ferrans & Powers, 1993; Jablonski, 2007), while two studies using health status instruments found that quality of life actually improved the longer one was on dialysis (Morsch et al., 2006; Walters et al., 2002). These later studies may have been measuring an improvement in uremic symptoms rather than improvement in overall quality of life. Reasons for the insignificant findings in this study may be due to the familiarity of the dialysis clinic and the rapport developed between participants and the dialysis staff and fellow patients. Thus, instead of time on dialysis becoming a growing burden, time brings a sense of familiarity and even an extended social support system. In addition, those who have been on dialysis for a longer period of time may have had more time to adjust psychologically to their new lifestyle.

The revised Wilson and Cleary model of health-related quality of life. The conceptual framework guiding this study was the revised Wilson and Cleary model of health-related quality of life (Ferrans et al., 2005). Although the main antecedents to

overall quality of life in this model are health factors, the model also includes characteristics of the individual and characteristics of the environment which make it a holistic schema for understanding quality of life. The framework provided guidance in selecting variables that may impact overall quality of life. Together, the variables explained 61% of the variance in quality of life for persons with ESRD. This is an important finding, as other ESRD quality of life studies have only reported R^2 values between .03 (Sesso et al., 2003) and .28 (Jablonski, 2007). These studies did not use as many variables as the present study.

Implications for Nursing

Quality of life is a complex construct with numerous antecedents. It should be an important outcome measure for all persons with ESRD to ensure that the healthcare resources dedicated to this population are providing a sense of well-being and satisfaction with life. Ascertaining quality of life requires input from the patient, and thus cannot be assessed independently by a clinician. Indeed, “when determining quality of life of an individual, that person’s own judgment is the only one that is ethically justifiable” (Ferrans, 2005, p. 23). Instruments are available that can assist in quantifying the assessment, such as the Quality of Life Index- Dialysis version. Although developed for research purposes, the QLI-D could be used to monitor individual changes in quality of life over time in a clinical setting, such as an outpatient dialysis center. If used in this manner, a valid and reliable short version may need to be developed as the instrument has 68 questions.

Symptom burden can be extreme in persons on dialysis. Individuals should be assessed for symptoms every dialysis session and a plan of care communicated to all members of the healthcare team. Those on dialysis need to be encouraged to discuss both physical and emotional symptoms and not accept them as a routine part of dialysis. A team focus towards symptom management may offer a more comprehensive approach for alleviating physical symptoms and provide emotional support for dealing with the psychological burden associated with ESRD.

Anxiety and depression are two symptoms that require special vigilance. Their impact on overall quality of life may be quite significant, and thus, persons on dialysis should be intentionally screened for both disorders. Assessing for symptoms associated with anxiety is especially important because anxiety may be more prevalent than depression in this population. Persons with ESRD are at an added risk for being under-diagnosed for both anxiety and depression due to the nondescript symptoms, such as feeling tired and sleeping more, which may be accepted as normal consequences of dialysis. In addition, patients may be embarrassed to discuss these feelings with their health care providers or consider their feelings trivial in relation to other physical problems. However, emotional health appears to have a large influence on quality of life. A comfortable rapport should be developed with each person to allow expression of such feelings. Pharmacological and non-pharmacological interventions should be explored in collaboration with the health care team until psychological needs are met. Including the family in these discussions may help detect changes in behavior not reported by the person on dialysis and ensure appropriate support from family members.

Fatigue is highly prevalent in the dialysis population. Besides having a physical impact, this debilitating symptom can also take an emotional toll. Assessing individuals for their level of fatigue should be conducted on a frequent basis. In addition, assisting individuals to identify their “normal” level of fatigue so that changes to this level can be recognized may ensure early detection of increased fatigue. Examining factors that may contribute to the intensity, duration, timing, and character of fatigue may aid in developing interventions for lessening post-dialysis fatigue. When fatigue cannot be adequately controlled, providing emotional support through active listening may provide some empathetic relief and build a trusting nurse-patient relationship.

Determining general health perceptions may be an important way for nurses to gain insight into patients’ health experiences. According to the revised Wilson and Cleary model (Ferrans et al., 2005), general health perception is highly subjective and takes into consideration biological factors, symptoms, functional status, as well as other undetermined factors. Thus this model is a comprehensive, patient-centered measure that may provide a holistic view for nurses. According to this study, a person’s perception of general health has significant bearing on overall quality of life, and therefore, it becomes a unique indicator of well-being. Low perceptions of general health may warrant further exploration to determine underlying causes. High perceptions of general health may provide additional validation that overall quality of life is acceptable.

Family relationships were an important source of support for persons with ESRD in this study. Including family members, as appropriate, in determining meaningful plans of care may enhance quality of life outcomes. When important family members cannot

come to the dialysis center, finding alternative methods for communication, such as electronic mail, can ensure continued engagement of the family member in the person's care.

Of all the variables included in this study, three were particularly important in explaining overall quality of life: (a) anxiety, (b) depression, and (c) general health perception. This finding speaks powerfully of the mind-body connection. None of the biological, physiological, functional, or demographic variables adequately explained quality of life. In the end, each person's sense of internal emotional equilibrium ultimately determined overall quality of life. This conclusion corroborates a meta-analysis of 12 studies which found that mental health had a much greater impact on quality of life (which was distinguished from health status) than physical function (Smith, Avis, & Assmann, 1999). This same study found that physical functioning had a greater impact on health status than overall quality of life. The meta-analysis included five different chronic diseases, although ESRD was not represented. These studies coupled with the results of the present study provide support for a holistic approach to quality of life, in that one's quality of life cannot be determined by health status alone. In addition, it helps to explain why quality of life studies in persons with ESRD have had mixed results. Mainly, researchers have not made a distinction between quality of life and health status, when they are indeed different constructs which are influenced by different antecedents.

Nursing has the potential to directly influence quality of life through interventions that may help patients rebalance their lives. Innovative therapies which use holistic

approaches to healing may promote healthier adaptations to ESRD. Examples of possible interventions include meditation, energy work, music therapy, support groups, and spiritual counseling. Exploration of these complementary approaches to care may reveal beneficial interventions that might improve overall quality of life.

Recommendations for Future Research

The term *quality of life* needs to be clearly defined in all future studies examining this variable. The majority of quality of life studies in persons with ESRD have equated quality of life with health status and/ or physical function. This physically-oriented approach to quality of life has been a confusing misuse of the term thereby yielding conflicting results. Additional studies of quality of life in persons with ESRD that incorporate a holistic worldview are needed. These future studies need to describe quality of life using a corresponding instrument that measures more than health status, such as the QLI-D. Factors affecting quality of life from this holistic perspective need to continue to be identified.

The present study used 15 variables representing various antecedents of quality of life according to the revised Wilson and Cleary conceptual framework for health-related quality of life (Ferrans et al., 2005). Three variables were important determinants of overall quality of life: (a) anxiety, (b) depression, and (c) general health perception. Because only three were significant in the overall model, other independent variables which might further explain quality of life need to be identified and tested.

None of the characteristics of the individual or characteristics of the environment selected for this study were significant. The effect of age, however, is still not clear.

Further studies examining differences in younger and older persons and perceptions of quality of life may provide additional understanding. Trending these perceptions over time may assist clinicians in understanding how persons cope with dialysis and chronicity as they age.

While marital status was not a significant variable in determining quality of life, additional studies looking at the broader concept of social support, such as that provided by friends and family, may provide better information. The role that the dialysis center milieu plays in social support also warrants further investigation. Tailoring dialysis procedures to facilitate and encourage patient-to-patient interactions and patient-to-staff interactions may foster a greater perception of social support.

Other individual and environmental characteristics need to be identified that may affect quality of life. Given the results of this study, characteristics that influence psychological health may prove more helpful in explaining quality of life. For example, important characteristics of the individual may be coping, spirituality, or role strain. An influential characteristic of the environment may be place of dialysis. For instance, persons on in-center dialysis may have a different quality of life than persons on home hemodialysis. Further examination of these factors may yield greater insight into individual or environmental characteristics affecting quality of life.

The convenience sample in this study was different from the U.S. ESRD population, thus limiting generalizability. There were more African Americans and more women. In addition, regional differences, such as religious preferences, may have affected perceptions of health and quality of life. Studies are needed which use samples

consisting of more White, male participants and from other regions of the country. Quota sampling would help to ensure a more representative ESRD sample.

In addition to further exploration of characteristics of the individual and characteristics of the environment, health-related variables also need additional study. The role of albumin is not clear. Further studies need to investigate the impact of albumin on overall quality of life, especially since this nutritional biomarker can often be modified through diet therapy. Prealbumin levels also warrant additional study. Prealbumin may be a more precise indicator of malnutrition than albumin (Collins, 2001) and provide better information as a biological factor affecting quality of life.

General dialysis symptoms and fatigue were not significant variables in explaining overall quality of life. Although quite prevalent within the sample, they did not factor in to the total model. Further exploration of symptom burden and its impact on persons with ESRD is warranted. Although most symptoms may be tolerable, there may be a threshold at which symptom load is unmanageable and impacts quality of life. Future researchers may want to categorize persons on dialysis into groups based on length of time on dialysis. This methodology would assist in explaining adaptation to symptoms over time.

Anxiety and depression consistently explained much variation in overall quality of life. Anxiety is a new finding associated with quality of life studies in persons with ESRD. Additional studies are needed to validate the effect of anxiety on quality of life. Depression is a well documented contributor to poor quality of life, and the current study lends further support. Randomized controlled studies which provide non-

pharmacological treatments for alleviating depression may provide important information on effective interventions in the ESRD population.

Functional status was measured with two instruments, and neither scale was significant in explaining quality of life. Validity issues with the Inventory of Functional Status- Dialysis need to be resolved and the revised scale needs to undergo subsequent reliability and validity testing. No studies were found using the Palliative Performance Scale (PPS) with persons on dialysis. Because this study yield similar PPS scores to other studies using the Karnofsky Performance Scale, continued testing of the PPS in the ESRD population is warranted. The impact of functional status on quality of life remains unclear, and future studies are needed to further examine this relationship. Stratifying participants into distinct functional categories may demonstrate differences in quality of life not clearly seen with a continuous measurement.

General health perception appears to be an important factor in determining quality of life. Further validation of this relationship is warranted through additional study. Differences in how persons with ESRD rate their health compared to how health care providers rate their patients' health may provide interesting comparisons. Determining reasons for varying health perceptions among similarly functioning individuals may provide insight into the psychological dimension of coping with chronic illness.

An exciting avenue for future research is to examine the mind-body connection and its relationship to quality of life. Further validation of this association is needed and potential interventions need to be designed for persons with ESRD. The inclusion of complementary therapies during dialysis may offer additional defense against

psychological issues associated with chronic kidney disease, bolster general health perception, and positively impact quality of life.

In contrast, examination of the impact of poor health perceptions and high levels of anxiety and depression on quality of life are needed. Determining if one or a combination of these factors is most predictive of quality of life would provide additional information. Studies which test interventions that may halt or reverse these factors and the effect of such interventions on quality of life are needed. In addition, determining when a poor quality of life may not be reversible and if this condition is related to the end of life is crucial work. Such determinations may assist health care providers in identification of the dying trajectory. Once identified, interventions can be put into place, such as early hospice referrals, to promote a good death (Kring, 2006).

The preceding paragraphs have discussed various portions of the revised Wilson and Cleary model (Ferrans et al., 2005). Each antecedent needs continued research to determine which factors can best determine overall quality of life. In addition, the model as a whole needs further testing in the ESRD population, as well as other populations. No previous studies were found that used this conceptual framework to inform variable selection and guide statistical analyses. Thus, further studies using this model are needed. Formal testing using structural equation modeling (SEM) would elucidate the strength of the hypothesized relationships in the model (Munro, 2005). Unlike path analysis, SEM allows for non-recursive pathways which may be important to understand how people adjust to chronic illness. That is, persons with a debilitating illness may readjust their general health perception as a way to cope with changes in life

circumstances. This adjusted perception may positively influence symptom experience, thus reversing the dominant causal flow of the model. In addition to validating the theoretical constructs of the model, SEM can test the measurement model (Munro, 2005) by taking into consideration differences in error rates and determining how well the data fit the theoretical model. SEM also allows for testing with different populations to ascertain if the model performs equally well among various subgroups. This determination may help explain differences in various illnesses and among various ESRD subpopulations. Finally, by testing the strength of relationships, SEM may assist in creating a more parsimonious model by identifying weak associations for deletion.

Based on the outcomes of this study, an additional category may need to be added to the model which includes psychological factors. Although two psychological factors important in the present study (anxiety and depression) were incorporated as part of symptom factors, the overall model has a distinctly physiological bias. Separating out psychological factors would give these factors greater prominence in explaining quality of life and encourage researchers to include them as variables in studies of quality of life. Further theoretical work would need to occur before hypothesizing where psychological factors would best fit in the model.

Summary

The purpose of this study was to describe the quality of life in persons with ESRD and examine factors which influence quality of life. Participants reported a relatively good quality of life, considering their high symptom burden, decreased functional status, and moderate general health perception. Anxiety, depression, and perception of health

had the greatest impact on overall quality of life, suggesting that psychological factors may better predict quality of life than physiological factors. Therefore, incorporating psychosocial assessments into routine dialysis care and initiating interventions to rebalance and stabilize thought and mood may assist persons with ESRD to experience a higher quality of life. Future studies should continue to identify variables that influence quality of life, determine interventions that enhance a person's sense of well-being, as well as illuminate the relationship between quality of life and end of life.

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APPENDIX A

Dialysis Demographic Form

Dialysis Demographic Form**Part A:**

To be completed by PI or RA from the medical record.

1. Today's date: _____
2. Age: _____ in years
3. Gender:
☐ Male (1)
☐ Female (0)
4. Time on hemodialysis: _____ in months
Include all months on hemodialysis, including episodes separated by periods of peritoneal dialysis or transplantation.
5. Most recent serum albumin level: _____ grams/ liter

Date of collection: _____
6. Most recent hemoglobin level: _____ grams/ dl

Date of collection: _____
7. Field Notes. Include questions that were problematic for the participant to answer, others issues that arose during data collection.

Dialysis Demographic Form

Part B:

To be asked of participants.

1. What race or ethnicity do you consider yourself?
 - ☐ African American/ Black (1)
 - ☐ American Indian (3)
 - ☐ Asian (4)
 - ☐ Caucasian/ White (0)
 - ☐ White Hispanic (2)
 - ☐ Non-white Hispanic (5)
 - ☐ Other: _____ (6)
 - ☐ Prefer not to answer (9)
2. What is your marital status?
 - ☐ Never married (1)
 - ☐ Married (0)
 - ☐ Divorced/ separated (2)
 - ☐ Widowed (3)
 - ☐ Prefer not to answer (9)
3. If female, have you had a menstrual period in the past 12 months?
 - ☐ Yes (1)
 - ☐ No (includes hysterectomies) (0)
 - ☐ I do not know (8)
 - ☐ Prefer not to answer (9)
 - ☐ Not applicable, I am male (7)
4. How likely are you to receive a kidney transplant?
 - ☐ Very likely (4)
 - ☐ Somewhat likely (3)
 - ☐ Probably not likely (2)
 - ☐ Not likely (1)
 - ☐ I do not know (8)
 - ☐ Prefer not to answer (9)

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5. Look at the Annual Family Income chart. Is your household income more than the indicated amount for the number of people in your home? Include any wages, Social Security, pensions, and interests or dividends on savings and investments.
- ☐ Yes, family income is equal to or more than the amount shown (0)
 - ☐ No, family income is not more than the amount shown (1)
 - ☐ Do not know (8)
 - ☐ Prefer not to answer (9)

Number of People in Family	Annual Family Income
1 (only yourself)	\$10, 210
2	13, 690
3	17, 170
4	20, 650
5	24, 130
6	27, 610
7	31, 090
8	34, 570
For each additional person, add	3, 480

APPENDIX B

Dialysis Symptom Index

Dialysis Symptom Index**The University of Pittsburgh Medical Center****VA Pittsburgh Healthcare System**

Patient Id: _____
Today's Date: _____
Code: _____
Interviewer Id: _____

Instructions

Below is a list of physical and emotional symptoms that people on dialysis may have. For each symptom, please indicate if you had the symptom during the past week by circling “yes” or “no.” If “yes”, please indicate how much that symptom bothered you by circling the appropriate number.

<i>During the past week: Did you experience this symptom?</i>		<i>If “yes”: How much did it <u>bother</u> you?</i>				
		Not At All	A Little Bit	Some- what	Quite a Bit	Very Much
1. Constipation	NO					
	YES →	1	2	3	4	5
2. Nausea	NO					
	YES →	1	2	3	4	5
3. Vomiting	NO					
	YES →	1	2	3	4	5
4. Diarrhea	NO					
	YES →	1	2	3	4	5
5. Decreased appetite	NO					
	YES →	1	2	3	4	5
6. Muscle cramps	NO					
	YES →	1	2	3	4	5
7. Swelling in legs	NO					
	YES →	1	2	3	4	5
8. Shortness of breath	NO					
	YES →	1	2	3	4	5
9. Lightheadedness or dizziness	NO					
	YES →	1	2	3	4	5
10. Restless legs or difficulty keeping legs still	NO					
	YES →	1	2	3	4	5

<i>During the past week: Did you experience this symptom?</i>		<i>If “yes”: How much did it <u>bother</u> you?</i>				
		Not At All	A Little Bit	Some- what	Quite a Bit	Very Much
11. Numbness or tingling in feet	NO					
	YES →	1	2	3	4	5
12. Feeling tired or lack of energy	NO					
	YES →	1	2	3	4	5
13. Cough	NO					
	YES →	1	2	3	4	5
14. Dry mouth	NO					
	YES →	1	2	3	4	5
15. Bone or joint pain	NO					
	YES →	1	2	3	4	5
16. Chest pain	NO					
	YES →	1	2	3	4	5
17. Headache	NO					
	YES →	1	2	3	4	5
18. Muscle soreness	NO					
	YES →	1	2	3	4	5
19. Difficulty concentrating	NO					
	YES →	1	2	3	4	5
20. Dry skin	NO					
	YES →	1	2	3	4	5
21. Itching	NO					
	YES →	1	2	3	4	5
22. Worrying	NO					
	YES →	1	2	3	4	5

During the past week: Did you experience this symptom?		If “yes”: How much did it <u>bother</u> you?				
		Not At All	A Little Bit	Some -what	Quite a Bit	Very Much
23. Feeling nervous	NO					
	YES →	1	2	3	4	5
24. Trouble falling asleep	NO					
	YES →	1	2	3	4	5
25. Trouble staying asleep	NO					
	YES →	1	2	3	4	5
26. Feeling irritable	NO					
	YES →	1	2	3	4	5
27. Feeling sad	NO					
	YES →	1	2	3	4	5
28. Feeling anxious	NO					
	YES →	1	2	3	4	5
29. Decreased interest in sex	NO					
	YES →	1	2	3	4	5
30. Difficulty becoming sexually aroused	NO					
	YES →	1	2	3	4	5

APPENDIX C

Hospital Anxiety and Depression Scale

Choose one response from the four given. You should give an immediate response and not think too long about the answers. You should answer how it currently describes your feelings.

A	I feel tense or 'wound up':	
<input type="checkbox"/>	Most of the time	3
<input type="checkbox"/>	A lot of the time	2
<input type="checkbox"/>	From time to time, occasionally	1
<input type="checkbox"/>	Not at all	0

D	I still enjoy the things I used to enjoy:	
<input type="checkbox"/>	Definitely as much	0
<input type="checkbox"/>	Not quite so much	1
<input type="checkbox"/>	Only a little	2
<input type="checkbox"/>	Hardly at all	3

A	I get a sort of frightened feeling as if something awful is about to happen:	
<input type="checkbox"/>	Very definitely and quite badly	3
<input type="checkbox"/>	Yes, but not too badly	2
<input type="checkbox"/>	A little, but it doesn't worry me	1
<input type="checkbox"/>	Not at all	0

D	I can laugh and see the funny side of things:	
	As much as I always could	0
	Not quite so much now	1
	Definitely not so much now	2
	Not at all	3

A	Worrying thoughts go through my mind:	
	A great deal of the time	3
	A lot of the time	2
	From time to time, but not too often	1
	Only occasionally	0

D	I feel cheerful:	
	Not at all	3
	Not often	2
	Sometimes	1
	Most of the time	0

A	I can sit at ease and feel relaxed:	
	Definitely	0
	Usually	1
	Not Often	2
	Not at all	3

D	I feel as if I am slowed down:	
	Nearly all the time	3
	Very often	2
	Sometimes	1
	Not at all	0

A	I get a sort of frightened feeling like 'butterflies' in the stomach:	
	Not at all	0
	Occasionally	1
	Quite Often	2
	Very Often	3

D	I have lost interest in my appearance:	
	Definitely	3
	I don't take as much care as I should	2
	I may not take quite as much care	1
	I take just as much care as ever	0

A	I feel restless as I have to be on the move:	
	Very much indeed	3
	Quite a lot	2
	Not very much	1
	Not at all	0

D	I look forward with enjoyment to things:	
	As much as I ever did	0
	Rather less than I used to	1
	Definitely less than I used to	2
	Hardly at all	3

A	I get sudden feelings of panic:	
	Very often indeed	3
	Quite often	2
	Not very often	1
	Not at all	0

D	I can enjoy a good book or radio or TV program:	
	Often	0
	Sometimes	1
	Not often	2
	Very seldom	3

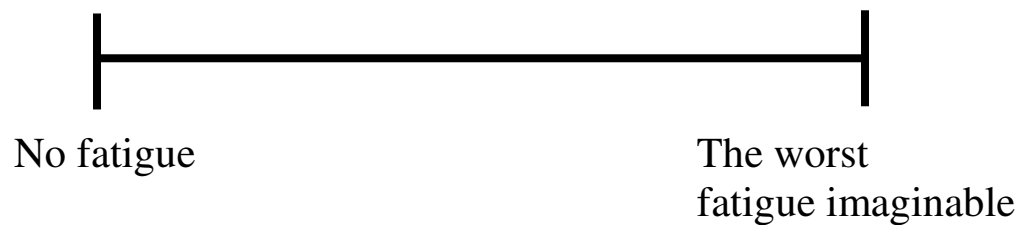
APPENDIX D

Fatigue Visual Analog Scale

During the past month, how much fatigue did you experience over the course of a typical week?

Place an X on the line that shows how much fatigue you had.

- If you had no fatigue, circle “no fatigue.”
- If you had the worst fatigue imaginable, circle, “the worst fatigue imaginable.”



APPENDIX E

Inventory of Functional Status- Dialysis

INSTRUCTIONS: Common activities are listed below. Please circle the answer that best describes the extent to which you actually performed these activities **IN A WEEK TYPICAL FOR YOU IN THE PAST MONTH.**

	IN A TYPICAL WEEK IN THE PAST MONTH				
	Did not do	Did with a lot of help	Did, with some help	Did by myself	Not applicable for me
1. Showered or bathed	1	2	3	4	0
2. Got dressed	1	2	3	4	0
3. Used the toilet	1	2	3	4	0
4. Did light housework (For example, make the bed, pick up things)	1	2	3	4	0
5. Did moderate housework (For example, dust the furniture, vacuum, moderate home repairs)	1	2	3	4	0
6. Did the laundry	1	2	3	4	0
7. Washed the dishes	1	2	3	4	0
8. Prepared meals	1	2	3	4	0

	Did not do	Did with a lot of help	Did with some help	Did by myself	Not applicable for me
9. Took care of household business (For example, pay the bills, do banking)	1	2	3	4	0
10. Did grocery shopping	1	2	3	4	0
11. Did shopping for things other than groceries	1	2	3	4	0
12. Ran errands (For example, went to post office, went to cleaners)	1	2	3	4	0
13. Attended church services	1	2	3	4	0
14. Participated in church activities or groups	1	2	3	4	0
15. Participated in social clubs (For example, neighborhood groups, bowling leagues)	1	2	3	4	0
16. Participated in volunteer or service organizations	1	2	3	4	0
17. Went out socially with friends or relatives	1	2	3	4	0

APPENDIX F

Palliative Performance Scale and Reformatted Palliative Performance Scale



Palliative Performance Scale (PPSv2)
version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity <i>with</i> Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Instructions for Use of PPS (see also definition of terms)

1. PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient which is then assigned as the PPS% score.
2. Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.

Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%.

Example 2: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.

Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'

3. PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that patient.
4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

Reformatted Palliative Performance Scale

1. Describe this person's ability to walk:
 - ☐ Full. Can walk without help when needed.
 - ☐ Reduced. Can walk and get to a chair on own, but may need help every now and then.
 - ☐ Mainly sits/ lies down. Does not walk much. Usually up in a chair or lying down in bed.
 - ☐ Mainly in bed. Rarely gets out of the bed. Spends most of the time sitting or lying in bed.
 - ☐ Totally in the bed. Never gets out of the bed.
2. Describe this person's activity and level of illness:
 - ☐ Normal activity & work. No evidence of disease.
 - ☐ Normal activity and work. Some evidence of disease.
 - ☐ Normal activity with effort. Some evidence of disease.
 - ☐ Unable to do normal job and work activities. Significant disease.
 - ☐ Unable to do hobby/ housework. Significant disease.
 - ☐ Unable to do any work. Extensive disease.
 - ☐ Unable to do most activity. Extensive disease.
 - ☐ Unable to do any activity. Extensive disease.
3. Self-care
 - ☐ Full. Can take care of self without assistance.
 - ☐ Occasional assistance necessary. Can take care of self, but occasionally needs assistance.
 - ☐ Considerable assistance required. Can take care of self, but needs some help every day.
 - ☐ Mainly assistance. Cannot take care of self without someone helping with most tasks.
 - ☐ Total care. Depends completely on others to provide care.

4. Intake

- ☐ Normal. Eats usual diet and normal amounts of food.
- ☐ Normal or reduced. Eats pretty much the same, or sometimes not as much.
- ☐ Minimal to sips. Eat very little, and sometimes only drink fluids.
- ☐ Mouth care only. Does not eat or drink.

5. Conscious level

- ☐ Full. Usually fully alert with no problems with thinking or remembering.
- ☐ Full or Confusion. Some confusion is present.
- ☐ Full or Drowsy +/- confusion. Often feels sleepy and not fully alert. May be confused.
- ☐ Drowsy or Coma. Is mostly drowsy, or rarely awake.

APPENDIX G

General Health Perception

How would you rate your health on a scale from 1 to 10, with 1= poor and 10= excellent? Circle the number that best describes your health.

1= poor health

2

3

4

5

6

7

8

9

10= excellent health

APPENDIX H

Quality of Life Index- Dialysis

Ferrans and Powers
QUALITY OF LIFE INDEX®
DIALYSIS VERSION - III

PART 1. For each of the following, please choose the answer that best describes how *satisfied* you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. The amount of energy you have for everyday activities?	1	2	3	4	5	6
4. Your ability to take care of yourself without help?	1	2	3	4	5	6
5. The likelihood you will get a kidney transplant?	1	2	3	4	5	6
6. The changes you have had to make in your life because of kidney failure (such as diet and need for dialysis)?	1	2	3	4	5	6
7. The amount of control you have over your life?	1	2	3	4	5	6
8. Your chances of living as long as you would like?	1	2	3	4	5	6
9. Your family's health?	1	2	3	4	5	6
10. Your children?	1	2	3	4	5	6
11. Your family's happiness?	1	2	3	4	5	6
12. Your sex life?	1	2	3	4	5	6
13. Your spouse, lover, or partner?	1	2	3	4	5	6
14. Your friends?	1	2	3	4	5	6
15. The emotional support you get from your family?	1	2	3	4	5	6

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HOW <i>SATISFIED</i> ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
16. The emotional support you get from people other than your family?	1	2	3	4	5	6
17. Your ability to take care of family responsibilities?	1	2	3	4	5	6
18. How useful you are to others?	1	2	3	4	5	6
19. The amount of worries in your life?	1	2	3	4	5	6
20. Your neighborhood?	1	2	3	4	5	6
21. Your home, apartment, or place where you live?	1	2	3	4	5	6
22. Your job (if employed)?	1	2	3	4	5	6
23. Not having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
24. Your education?	1	2	3	4	5	6
25. How well you can take care of your financial needs?	1	2	3	4	5	6
26. The things you do for fun?	1	2	3	4	5	6
27. Your chances for a happy future?	1	2	3	4	5	6
28. Your peace of mind?	1	2	3	4	5	6
29. Your faith in God?	1	2	3	4	5	6
30. Your achievement of personal goals?	1	2	3	4	5	6
31. Your happiness in general?	1	2	3	4	5	6
32. Your life in general?	1	2	3	4	5	6
33. Your personal appearance?	1	2	3	4	5	6
34. Yourself in general?	1	2	3	4	5	6

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PART 2. For each of the following, please choose the answer that best describes how *important* that area of your life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
HOW IMPORTANT TO YOU IS:						
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. Having enough energy for everyday activities?	1	2	3	4	5	6
4. Taking care of yourself without help?	1	2	3	4	5	6
5. Getting a kidney transplant?	1	2	3	4	5	6
6. The changes you have had to make in your life because of kidney failure (such as diet and need for dialysis)?	1	2	3	4	5	6
7. Having control over your life?	1	2	3	4	5	6
8. Living as long as you would like?	1	2	3	4	5	6
9. Your family's health?	1	2	3	4	5	6
10. Your children?	1	2	3	4	5	6
11. Your family's happiness?		2	3	4	5	6
12. Your sex life?	1	2	3	4	5	6
13. Your spouse, lover, or partner?	1	2	3	4	5	6
14. Your friends?	1	2	3	4	5	6
15. The emotional support you get from your family?	1	2	3	4	5	6
16. The emotional support you get from people other than your family?	1	2	3	4	5	6

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HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
17. Taking care of family responsibilities?	1	2	3	4	5	6
18. Being useful to others?	1	2	3	4	5	6
19. Having no worries?	1	2	3	4	5	6
20. Your neighborhood?	1	2	3	4	5	6
21. Your home, apartment, or place where you live?	1	2	3	4	5	6
22. Your job (if employed)?	1	2	3	4	5	6
23. Having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
24. Your education?	1	2	3	4	5	6
25. Being able to take care of your financial needs?	1	2	3	4	5	6
26. Doing things for fun?	1	2	3	4	5	6
27. Having a happy future?	1	2	3	4	5	6
28. Peace of mind?	1	2	3	4	5	6
29. Your faith in God?	1	2	3	4	5	6
30. Achieving your personal goals?	1	2	3	4	5	6
31. Your happiness in general?	1	2	3	4	5	6
32. Being satisfied with life?	1	2	3	4	5	6
33. Your personal appearance?	1	2	3	4	5	6
34. Are you to yourself?	1	2	3	4	5	6

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